ALZHEIMER'S SPECIAL CARE UNITS: DEMENTIA AND ALZHEIMER'S DISEASE IN RESIDENTIAL CARE AND ASSISTED LIVING FACILITIES

A Dissertation

by

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ABSTRACT

Residential Care and Assisted Living Facilities (RC/AL) are rapidly becoming one of the most popular long-term supports and services (LTSS) care modalities, particularly for individuals living with Alzheimer's disease or other forms of dementia. With the growing popularity of RC/ALs, the push toward these types of facilities over more expensive skilled nursing facilities, and the dramatically increasing prevalence of dementia, many Americans are turning to RC/ALs advertising Alzheimer's Special Care Units (SCUs) for care of their loved ones. However, the absence of a federal definition for what constitutes an SCU, the varying state-by-state regulation of these units, and the scarcity of studies exploring the characteristics and effectiveness of SCUs provides little evidence for what actually goes on in an SCU and whether or not sufficient protections are in place for a particularly vulnerable population, cognitively impaired adults.

This study explored RC/AL SCUs at the facility level and at the individual or resident level. The first part of the study examined facility level characteristics of SCUs and the absence or presence of dementia care features across RC/ALs that have an SCU. The distribution of dementia care features demonstrates the variability of care in SCUs.

The second part of the study compared SCU residents to non-SCU residents across: demographics, health-related characteristics, facility characteristics, falls, ER use, and hospital stays (non-ER). Residents in SCUs have similar demographic characteristics as non-SCU residents; however, these two groups differ in health-related characteristics with residents living in SCUs reporting poorer overall health, much

higher rates of incontinence and memory issues, and higher percentages of falls compared to non-SCU residents.

The third part of the study explored behavioral issues exhibited by RC/AL residents living in SCUs. The relationship between SCUs and four subgroups of behavioral issues (aggressive, physical, verbal, resistant to care) was explored, while controlling for demographics and health related characteristics. Behavioral issues are prevalent in SCUs.

The higher acuity of residents and the variability of care seen in this setting indicate that the current state of RC/AL SCUs may not be equipped to provide adequate care for individuals living with Alzheimer's disease or other dementias.

DEDICATION

I would like to dedicate this dissertation research project to my nephew, Arthur Edward Bronk. Arthur's presence in my life is a great joy and he has been a source of incredible inspiration. I hope to one day influence policy and the "standard world" with my research. This goal is emphasized by my desire to make this world a better place for my young nephew and to be an example of action and compassion.

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Finally, many thanks to my mother, Sun Edwards, and father, Frederick Edwards, for their encouragement and to my sisters, Julianna Bronk and Abigail Edwards, and brother, Jonathan Edwards, for their patience and love.

NOMENCLATURE

ADL	Activities of Daily Living
IADL	Instrumental Activities of Daily Living
LOS	Length of Stay
LTSS	Long Term Services and Supports
NH	Skilled Nursing Home Facility
RC/AL	Residential Care Facility or Assisted Living Facility
SCU	Special Care Unit or Memory, Dementia, Alzheimer's Care Unit

TABLE OF CONTENTS

Page

LIST OF FIGURES

LIST OF TABLES

1. INTRODUCTION

In the past 66 seconds, a person in the United States developed Alzheimer's disease, the 6th leading cause of death for people ages 65 years and older (Alzheimer's Association, 2015). By 2050, it is estimated that one individual living in America will develop this debilitating disease every 33 seconds (Alzheimer's Association, 2013). As the number of individuals diagnosed with Alzheimer's disease, the leading cause of dementia, has increased, the demand for memory care services in residential long-term care facilities has grown (Glenner, 1982; Kopetz et al., 2000). Residential Care and Assisted Living Facilities (RC/AL) are rapidly becoming one of the most popular long-term care modalities with over 30,000 facilities, and approximately 900,000 beds nationwide in 2010 (Park-Lee et al., 2011). Many of these RC/ALs offer specialized, memory care in the form of Alzheimer's Special Care Units (SCUs); however, little is known about these units and the ways in which the staffing, services, and environment in SCUs may differ from traditional RC/AL settings.

SCUs are advertised as models of safe and comfortable living with specialized staffing and services. However, the absence of a federal definition for what constitutes an SCU, the lack of regulation of these facilities, and the scarcity of studies exploring the characteristics of these units means there is little evidence for what actually goes on in an SCU. Facilities may advertise themselves as a model of care for persons with dementia; however, the definition or standard of care that these facilities can hold themselves to vary state by state or are absent (Mollica, Mollica, Johnson-Lamarche, &

O'Keeffe, 2005). In essence, with very little accountability, RC/AL SCUs can call themselves a model of care, when, in fact, these units could be providing the exact same or fewer services of a traditional RC/AL unit. As the RC/AL industry continues to grow, a clearer understanding and definition of SCUs is required. In order to better understand the state of this problem, RC/ALs and SCUs must be researched.

1.1 Background and Literature Review

1.1.1 Aging in the United States

The U.S. Census Bureau estimates that beginning in 2010, and for the following 20 years, approximately 10,000 people in America will turn 65 years old every single day. By 2050, the population of Americans over the age of 65 will more than double and those over the age of 85 will more than triple (Houser, Fox-Grage, & Ujvari, 2012). In 2005, the number of Americans over the age of 65 was 37 million (12% of the overall population); this group is estimated to grow to over 80 million by 2050 (19% of the overall population) (Passel & Cohn, 2008). With Americans living longer, there has been a steady increase in the incidence of Alzheimer's disease and dementia diagnoses (Hebert, Beckett, Scherr, & Evans, 2001).

1.1.2 Alzheimer's Disease and Other Dementias

Dementia is a condition characterized by cognitive impairment and loss of brain function (Mesulam, 1985). It is not a disease, but rather a group of symptoms the influence the body's mind and mental tasks, including reasoning and memory (Glenner, 1982). Alzheimer's disease (AD) is the most common cause of dementia (Glenner, 1982). According to the diagnostic recommendations set forth by the National Institute

of Aging (NIA) and the Alzheimer's Association, dementia is diagnosed when symptoms of cognitive impairment are present (i.e. functional decline, impaired reasoning, etc.) (McKhann, et. al., 2011). Many of these individuals diagnosed with dementia have AD. Unfortunately, the difference between all-cause dementia and Alzheimer's disease caused dementia is difficult to define without the use of expensive neuropsychological testing, specialized clinical investigators, and advanced imaging (McKhann et. al., 2011). While new criteria have been set forth for both all-cause dementia and Alzheimer's disease caused dementia, these criteria very often overlap with the presence of cognitive and neuropsychiatric decline (Alzheimer's Association, 2015; McKahann et. al., 2011). With this overlap present in the clinical, diagnostic realm of health care, dementia, cognitive impairment, and Alzheimer's disease are very often grouped together when studied in the field of long-term supports and services. In this study, adults living in RC/ALs with cognitive impairment are studied and people living with dementia and AD are grouped together.

The costs associated with Alzheimer's disease and dementia are tremendous, with between $157 billion and $215 billion attributed to informal and formal care for people living with dementia in 2010 (Hurd, Martorell, Delvande, Mullen, & Langa, 2013). Of this cost of $157-215 billion, it is estimated that $11 billion was paid by Medicare (Hurd et al., 2013). In 2015, total Medicaid spending for beneficiaries living with Alzheimer's disease and dementia was over $40 billion (Alzheimer's Association, 2015). Also, "average Medicaid payments per person for Medicare beneficiaries with Alzheimer's disease and other dementias ($11,021) were 19 times as great as average

Medicaid payments for Medicare beneficiaries without Alzheimer's disease and other dementias ($574)" (Alzheimer's Association, 2015, p. 45). Future projections of total cost associated with this disease are expected to increase from $226 billion in 2015 to over $1 trillion by 2050 (Alzheimer's Association, 2015). With the growing prevalence, death rate, and cost of Alzheimer's disease and other dementias in America, it is imperative to explore not only the care modalities available to people living with this deadly disease, but also the protections put in place to safeguard these individuals who may not be able to advocate for themselves due to the development of dementia and cognitive impairment.

1.1.3 Dementia in Residential Care and Assisted Living Facilities

Estimates of the prevalence of Alzheimer's disease and other dementias in the RC/AL setting vary across studies and methods of detecting dementias. It is estimated that 23-42% of RC/AL residents have moderate to severe cognitive impairment or diagnosable dementia (Zimmerman et al., 2003). A study using the 2010 National Survey of Residential Facilities (NSRCF) reports that 70% of RC/AL residents have some form of cognitive impairment with 19% of RC/AL residents living with severe cognitive impairment (Zimmerman, Sloane, & Reed, 2014). Other studies, such as one in Maryland found two thirds of all RC/AL residents have dementia, using psychiatric examinations and case findings (Rosenblatt et al., 2004).

Despite these differences, the overall finding is clear: a substantial population of RC/AL residents suffers from some type of cognitive impairment, most commonly Alzheimer's disease or other dementias. These percentages are increasing as more and

more residents enter the RC/AL market and as life expectancy increases across the United States.

1.1.4 Residential Care and Assisted Living Facilities

Researchers define RC/ALs as "a congregate residential setting that provides or coordinates personal services, 24-hour supervision and assistance (scheduled and unscheduled), activities, and health related services; designed to minimize the need to move; designed to accommodate individual residents' changing needs and preferences; designed to maximize residents' dignity, autonomy, privacy, independence, and safety; and designed to encourage family and community involvement" (Hawes et al., 2003, p. 875). There has been rapid growth in the RC/AL industry as consumer demand continues to increase for this residential living arrangement (Hawes et al., 2003; Hawes & Phillips, 2007; Kopetz et al., 2000). This growth is also due to the push away from nursing home (NH) use and toward other long-term care options, as seen in the 1999 U.S. Supreme Court ruling of *Olmstead v. L.C.* (Smith, Lakin, Larson, & Salzar, 2011). This Olmstead decision determined that, under the Americans with Disabilities Act (ADA), "unjustifiable institutionalization of a person with a disability who, with proper support, can live in the community is discrimination" (Smith et al., 2011, p. 53). The growth of the RC/AL industry can be attributed to a combination of factors including: consumer preference; court decisions, including the Olmstead cases; and public policy that focused on preadmission screening, NH diversion, and rebalancing waiver programs (Olmstead v. L.C., 1999; Hawes & Phillips, 2007; Kasper & O'Malley, 2006; Summer, 2005).

This RC/AL industry was initially unregulated by the government (Hawes & Phillips, 2007). As the number of RC/ALs grew, state standards and licensure measures were enacted to regulate these facilities (Hawes & Phillips, 2007; Mollica, 2002; Mollica & Johnson-LaMarche, 2005). However, there are currently no federal regulations for RC/ALs in the United States (Hawes & Phillips, 2007). The lack of a concrete legal definition and the extreme variability across RC/ALs are two of the many issues that stem from the absence of federal regulation (Hawes & Phillips, 2007; Hyde, Perez, & Forester, 2007).

1.1.5 Special Care Units in Residential Care and Assisted Living Facilities

In 2004, the Public Policy Institute reviewed RC/ALs at the national level and concluded, "Despite the large number of [RC/AL] residents with dementia, no consistent standards exist to ensure that the residences that serve them provide the services, trained staff, and environment to meet their needs" (Wright, 2004, pgs. 5-6). This lack of quality standards for RC/AL facilities leaves residents unprotected and at the mercy of these sometimes large, corporate, for-profit facilities focused on profitability.

According to current federal regulations, there is no concrete, standardized definition which can be attached to the term Special Care Unit (SCU) within RC/ALs. Many names including memory care unit, Alzheimer's care unit, and dementia care unit, have been attached to the specialized services provided in a unit designed to care for residents with cognitive impairment. At the state level, the definition, services, agreements, and requirements included in SCU policies vary from state to state (Mollica, Johnson-Lamarche, & O'Keeffe, 2005; National Center for Assisted Living, 2012). For

example, some states have additional education and training requirements for managers and staff members of SCUs. Other states have gradual levels of service requirements based on number of residents served. Several states include particular certification requirements for facilities to advertise to consumers as Alzheimer specific SCUs (Mollica, Johnson-Lamarche, & O'Keeffe, 2005; NCAL, 2012).

In Alabama, RC/ALs that provide care for residents with dementia must have a specialty-care facility license, a medical director, and at least one registered nurse (Mollica, Johnson-Lamarche, & O'Keeffe, 2005; NCAL, 2012). Alabama SCUs require six continuing education hours annually and have minimum daytime staff ratios with two staff for units with less than 16 residents and one staff for every eight residents for units with more than 16 residents (Mollica, Johnson-Lamarche, & O'Keeffe, 2005; NCAL, 2012).

In Alaska and Arizona, there are no specific provisions for RC/ALs that provide care for people with dementia in SCUs beyond traditional RC/AL requirements (Mollica, Johnson-Lamarche, & O'Keeffe, 2005; NCAL, 2012).

In Texas, RC/ALs must be certified as a Type B facility if they seek to market, advertise, or publicize to consumers the option of SCUs for people living with Alzheimer's disease or dementia (Mollica, Johnson-Lamarche, & O'Keeffe, 2005; NCAL, 2012). In other words, RC/AL facilities with SCUs must be certified to care for individuals who are not able to evacuate without assistance in the case of an emergency. Also, the facility must provide a disclosure statement with information concerning the nature of care/treatment for residents living with Alzheimer's disease or other dementias

(NCAL, 2012). Direct care staff are required to have completed high school (or high school equivalent certification – GED), completed four hours of dementia specific orientation material, 16 hours of supervised on-the-job employment, and an annual 12 hours of in service continuing education concerning Alzheimer's disease (NCAL, 2012). SCUs are neither checked nor reviewed on a regular basis. No enforcement takes place unless a complaint of abuse, neglect, exploitation, or a violation of state standards is made against a facility (Texas Code § 92.103).

State level policies affecting RC/ALs continue to fluctuate with 18 states making regulatory, statutory, or policy changes during 2012 (National Center for Assisted Living, 2013). Many of these changes were seen in survey and inspection approaches as well as level of licensure for RC/ALs (NCAL, 2013). Very little change has been seen concerning RC/AL Alzheimer's disease care and SCU policies and procedures (NCAL, 2013).

1.1.6 Special Care Units in Nursing Home Facilities

Many skilled nursing home facilities (NH) have Alzheimer's specific SCUs; however, research suggests these SCUs have no statistically significant difference between functional outcomes compared to traditional nursing home units, specifically when evaluating the speed of decline (Coleman & Barbaccia, 1990; Phillips et al., 1997). The results of a systematic review concerning the role and effectiveness of SCUs in NHs found very little evidence of better outcomes in SCUs and has led some researchers to argue the specialized care environment provided in SCUs is less important than the

implementation of best practice policies catered toward individuals living with dementia (Lai, Yeung, Mok, & Chi, 2009).

Regulation concerning NH SCUs vary state by state and can consist of licensure (initial inspection and survey before the opening of a facility), certification (regular survey inspection), disclosure statements (agreement between facility and consumer on policies and services), or an absence of regulation (Grande, 2002). Critics of NH SCUs voice similar concerns expressed in this study (Grande, 2002). With an absence of regulation, stakeholders are concerned that SCUs are used as a marketing ploy with little to no additional services provided to residents (Grande, 2002).

1.2 Specific Aims

This dissertation study has three specific aims.

1. Examine facility level characteristics of SCUs. Identify which RC/AL facilities have a "substandard" SCU (0-4 dementia care features) and which RC/AL facilities have a "standard" SCU (5 dementia care features). Identify which facility level characteristics affect the likelihood that a facility has (1) a "substandard" SCU, and (2) a "standard" SCU.
2. Examine individual level characteristics of residents living in SCU's and traditional, non-SCUs. Compare SCU residents to non-SCU residents across: demographics, health-related characteristics, facility characteristics, falls, ER use, and hospital stays (non-ER).
3. Identify, categorize, and study behavioral issues exhibited by RC/AL residents living in SCUs and non-SCUs. Find the association between SCU/non-SCU and

the four subgroups of behavioral issues (aggressive, physical, verbal, resistant to care), while controlling for demographics and health related characteristics.

The research question of the first aim was how RC/ALs with SCUs are different from RC/ALs without SCUs. Chapter 2 of this dissertation explored this issue by studying five features of SCUs – locked doors, personal monitoring devices, enclosed courtyards, higher staff to resident ratios, and specially trained staff members – and the facility characteristics of RC/ALs. This facility level analysis was important because it showed which facility characteristics and admission features affect the likelihood that SCUs have the five features of a "standard" SCU.

The research question of the second aim was whether residents living in SCUs are different from residents living in non-SCUs, across resident characteristics, facility characteristics, falls, ER use, and hospital use. This individual, resident level analysis was important because the absence of regulations in SCU settings may be leaving a gap of protection for residents in RC/AL SCU residents who have higher acuity and worse health outcomes.

The research question of the third aim was whether there is a positive or negative association between a resident living in an SCU and four behavioral issues (aggressive, physical, verbal and resistant to care), controlling for resident demographics and health related characteristics. Behavioral issues in RC/ALs were studied and categorized across RC/AL setting. The presence and severity of behavioral issues in RC/AL SCUs was evaluated across several models of controlling factors.

As America matures and the "Baby Boomer" generation begins to look for long-term care options, the need to address and better understand the current state of specialized memory long-term care will become more and more relevant and imperative. Little is known about the complexities surrounding the structure, quality, efficiency, and entry into SCUs. This gap in the literature leaves a glaring question mark concerning the well-being and protection of a particularly vulnerable population, cognitively impaired adults living with Alzheimer's disease or other dementias.

1.3 Conceptual Model

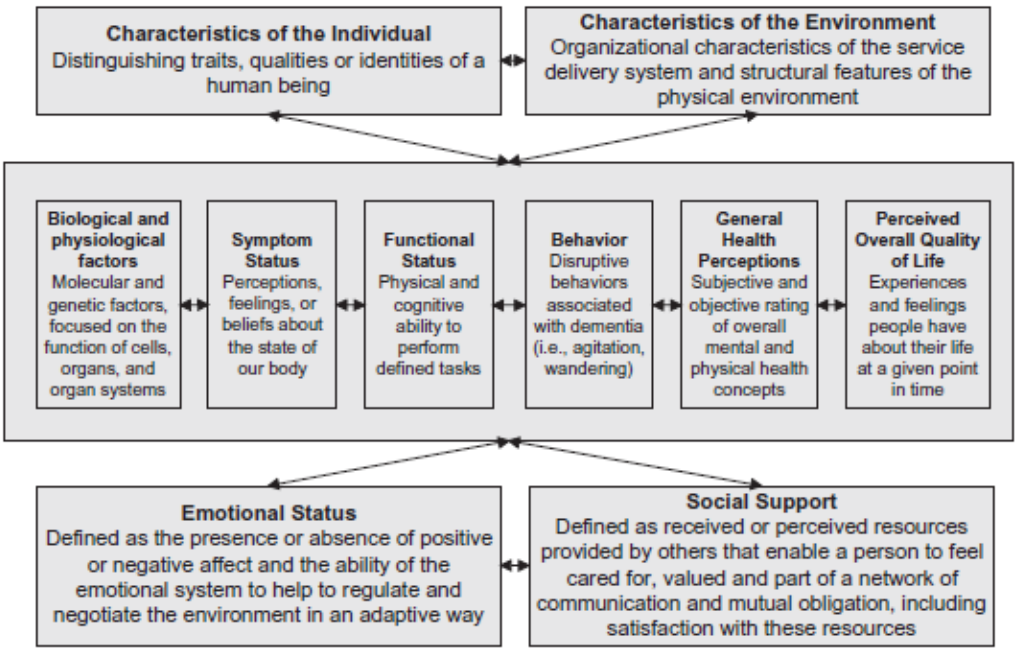

Figure 1. The long-term services and supports health-related quality of life conceptual model. As developed by Wilson and Cleary (1995) and adapted by Brod and colleagues (1999); with Patrick (1997).

Figure 1 Health-related quality of life (HRQoL) for older adults who receive long-term services and supports (LTSS) (Zubritsky et al., 2012)

The Health-Related Quality of Life (HRQoL) model includes several multidimensional domains of quality of life (QoL) including physical health, emotional health, well-being, health care status, satisfaction, and social support (Wilson & Cleary, 1995; Zubritsky et al., 2012). This model is used widely to address issues of QoL in the general adult population and was extended in order to study the intricacies and challenges associated with the long-term services and supports (LTSS) population and LTSS organizational environment (Wilson & Cleary, 1995; Zubritsky et al., 2012). This LTSS HRQoL model reflects the complexities of functional decline (cognitive and physical), the presence of multiple co-morbidities (including chronic illnesses), and LTSS structure and organization (Zubritsky et al., 2012).

Using this LTSS conceptual model as the overarching framework, Section 2, *Alzheimer's Special Care Units in Residential Care and Assisted Living Facilities,* focused on the characteristics of the structural environment. Section 2 used organizational characteristics and structural features of RC/ALs, both with and without SCUs present in the facility.

Section 3, *Alzheimer's Special Care Unit Residents Living in Residential Care and Assisted Living Facilities: Comparing SCU to Non-SCU Residents across Resident Characteristics, Falls, ER visits, and Hospital Stays,* focused on the characteristics of the individual. Section 3 used individual (resident) qualities, characteristics, and traits. This study explored the characteristics of the individual and compared individual characteristics across different settings of RC/AL. Resident characteristics include biological and physiological factors like age, gender, and other resident demographic

characteristics. This study also looked at symptom status and functional status by evaluating resident health-related characteristics including: overall health, assistance with activities of daily living (ADLs), memory problems, and falls resulting in a hip fracture or other injury.

Section 4, *Behavioral Issues in Alzheimer's Special Care Unit Residents Living in Residential Care and Assisted Living Facilities,* focused on characteristics of the individual as well as behavior, symptom status, and functional status. Section 4 analyzed the resident's physical functionality and cognitive capabilities as well as the presence of behavioral issues across RC/AL settings

1.4 Research Design

The research design of each of these research studies was based on a cross sectional, observational framework. The data analyses were based on secondary data from the 2010 National Survey of Residential Care Facilities (NSRCF). NSRCF facility and individual data were collected by the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics (NCHS), Division of Health Care Statistics. To be included in the NSRCF, residential care facilities must be registered, licensed, listed, certified, or otherwise regulated by the state; have four or more licensed, certified, or registered beds; have at least one resident currently living in the facility; and provide room/board with at least two meals a day, around the clock on-site supervision, and help with personal care or health related services.

The national study used a stratified two-stage probability sample design with interviews conducted in 2,302 facilities, approximately 5% of the national number of

RC/ALs in 2010. Facility size and region were the primary sampling strata with RC/ALs selected using systematic random sampling. Of the 3,605 randomly selected RC/ALs, 2,644 were eligible and 2,302 completed interviews via questionnaires (81% weighted response rate). Facilities were interviewed with questions about the facility and sampled residents. Facility staff responded to these questionnaires and residents were not interviewed (Zuckerbraun, LeBaron, Loft, & Sengupta, n.d.).

To safeguard data consistency and reliability, field observations, verification calls, management meetings, production reports, field memos, and field calls were used. Reliability of survey estimates were tested using the relative standard error (RSE) of the estimates and NCHS guidelines. The NSRCF was tested by a technical advisory panel made up of nine members. In addition to this panel and government staff at the Assistant Secretary for Planning and Evaluation (ASPE), the Agency for Healthcare Research and Quality (AHRQ), and the Center for Disease Control and Prevention's National Center for Health Statistics (NCHS), the survey data collection instruments were reviewed by seven experts in the field of long-term care.

Because the 2010 NSRCF data sets were secondary data, publicly available, and cleaned to protect the identity of individuals, the Institutional Review Board (IRB) of Texas A&M University exempted these studies from further review.

The study in Section 2 used descriptive statistics, pattern variable methodology, and logistic regression. Section 2 used the publicly available facility level data set from the 2010 NSRCF. The study in Section 3 used descriptive statistics and bivariate analyses. Section 3 used the publicly available individual, resident level data set from the

2010 NSRCF. The study in Section 4 used ordered logistic regression as its primary analytical methodology. Section 4 used individual, resident level data from the 2010 NSRCF. In order to protect the identity and health information associated with NSRCF participants, facility level data and individual level data from the 2010 NSRCF cannot be linked.

The research design in this study was used to objectively provide results and draw conclusions, as well as policy implications, for the present state of and future of RC/ALs, particularly RC/ALs with SCUs providing care to residents living with Alzheimer's disease and other forms of dementia.

1.5 Journal Style

These studies are presented in the format consistent with publication in *The Gerontologist.* These studies will be submitted to several potential journals for publication including: *The Gerontologist* and the *Journal of the American Geriatrics Society*.

2. ALZHEIMER'S SPECIAL CARE UNITS IN RESIDENTIAL CARE AND ASSISTED LIVING FACILITIES

Objective(s):

- *Examine facility level characteristics of SCUs.*
- *Identify which combinations of dementia care features are common in facilities that claim to have an SCU.*
- *Identify which facility level characteristics affect the likelihood that a facility (1) has a "substandard" SCU, and (2) has a "standard" SCU.*

Purpose of the Study: As America matures and the "Baby Boomer" generation continues to access long-term supports and services, it is imperative to address the well-being and protection of cognitively impaired adults in Residential Care and Assisted Living Facilities (RC/ALs). The purpose of this study is to explore the characteristics of RC/AL dementia specific Special Care Units (SCUs) at the facility level.

Design and Methods: Descriptive statistics and multivariate analyses including logistic regression were used in this cross sectional study of 2010 National Survey of Residential Care Facilities data. These methods were used to explore how many and what types of RC/ALs provided the "standard" or "substandard" level of SCU features of dementia care in their facilities.

Results: The logistic regressions show that facilities that claim to have an SCU are more likely to be larger, to be for-profit, to use physical restraints, and to regularly use drugs to control behavior. Of these facilities that claim to have an SCU, approximately 22%

had all five of the dementia care features and 13% had one, two, or none of the features. In this country, less than 5% of RC/ALs have a true, "standard" SCU (all five features) equipped to provide dementia care.

Implications: These analyses indicate that there are not enough true, "standard" SCUs to meet the growing demand for dementia care. The lack of these types of facilities and the absence of federal regulation for RC/AL SCUs leaves this vulnerable population at risk for substandard care and potential exploitation.

2.1 Introduction

The prevalence of Alzheimer's disease is rapidly growing in the United States. In 2010, 4.7 million Americans, or 1.5% of the total population, were living with AD (Hebert, Weuve, Scherr, & Evans, 2013). When this 2010 statistic was broken down into three age groups, 3% of people between the ages of 65-74, 17.6% of people between the ages of 75-84, and 32.3% of people over the age of 85 were living with AD (Hebert et al., 2013). In 2015, 5.3 million Americans were living with AD (1.6% of total population in the United States) (Alzheimer's Association, 2015). The number of people living with AD is expected to increase to 13.8 million, with approximately 7 million of these individuals over the age of 85, by 2050 (Hebert et al., 2013). When this projected 2050 estimate was broken down into three age groups, 3.3% of people between the ages of 65-74, 18.5% of people between the ages of 75-84, and 36.6% of people over the age of 85 were living with AD (Hebert et al., 2013). As American life expectancy increases, the presence of Alzheimer's disease will continue to increase, especially among those individuals over the age of 85 (Alzheimer's Association, 2015).

While deaths caused by stroke and heart disease decreased by 23% and 16% in the United States between 2000 and 2010, deaths caused by Alzheimer's disease increased by 68% during this time period (Alzheimer's Association, 2013). In 2014, 700,000 or one in three Americans died with Alzheimer's disease or dementia (Alzheimer's Association, 2014).

With increasing numbers of individuals living with Alzheimer's disease and dementia, the long term supports and services (LTSS) provided for individuals living

with cognitive impairment need to be studied and evaluated for quality and efficacy. One LTSS setting on the rise is the model of care provided in Residential Care and Assisted Living Facilities (RC/AL). The facility characteristics, care services, and outcome measures associated with the RC/AL care modality vary widely due to the absence of federal regulation and the diverse levels of state oversight and certification (Hawes & Phillips, 2007; Mollica, 2002; Mollica & Johnson-LaMarche, 2005; National Center for Assisted Living, 2012).

The rising demand for services catered toward people living with Alzheimer's disease or other types of dementia has spurred the development of Alzheimer's disease or dementia specific units very often referred to as Memory Care or Special Care Units (SCU). In 2010, approximately 17% of RC/ALs in the nation were facilities that only served residents with dementia or were facilities that had a separate unit specialized in memory care, an SCU separate from traditional RC/AL units (Park-Lee, Sengupta, & Harris-Kojetin, 2013).

While the SCU care modality is becoming more popular across the nation, not much is known about the facility characteristics seen in RC/ALs with SCUs or the services provided in this setting. The objectives of this study were to explore the characteristics of RC/AL SCUs at the facility level, evaluate the services provided in RC/AL SCUs, and compare RC/ALs with "standard" SCUs (five dementia care features present) and "substandard" SCUs (0-4 dementia care features present). This study focused on populations of cognitively impaired residents residing in an RC/AL setting.

Very often these populations include residents with Alzheimer's disease and other dementias.

2.1.1 Theoretical/Conceptual Framework

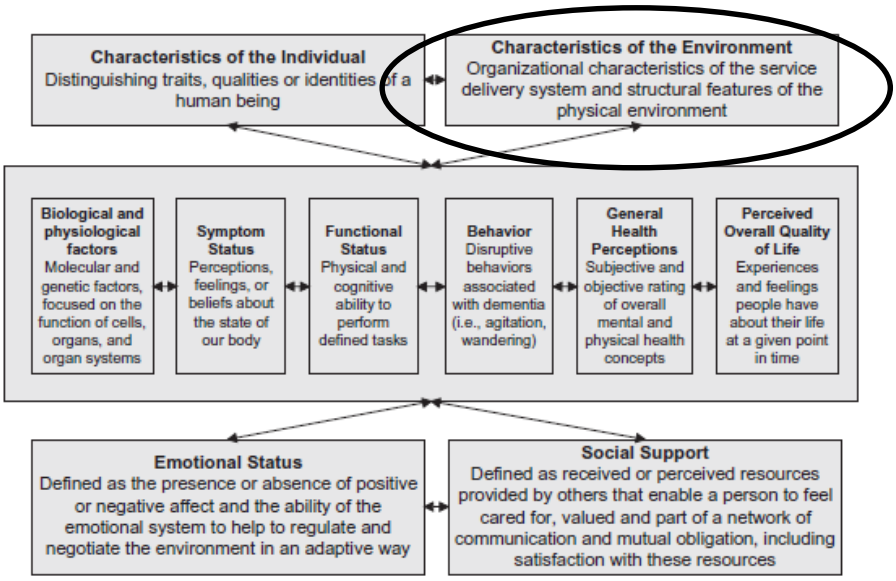

Figure 1. The long-term services and supports health-related quality of life conceptual model. As developed by Wilson and Cleary (1995) and adapted by Brod and colleagues (1999); with Patrick (1997).

Figure 2 Health-related quality of life (HRQoL) for older adults who receive long-term services and supports (LTSS) – 1st Tier (Zubritsky et al., 2012)

This study used an overarching framework of a health related quality of life long-term services and supports (HRQoL-LTSS) conceptual model and focuses on the characteristics of the environment. These analyses used organizational characteristics and structural features of RC/ALs to study the physical and structural aspects of SCUs as well as the care practices observed in this LTSS setting (Zubritsky et al., 2012).

The purpose of this study was to evaluate the characteristics of RC/AL SCUs at the facility level. This study focused on populations of cognitively impaired residents residing in an RC/AL setting and the absence or presence of dementia care features across RC/ALs that have an SCU.

2.1.2 Specific Aims

1. Examine facility level characteristics of SCUs.
2. Identify which RC/AL facilities have a "substandard" SCU (0-4 dementia care features) and which RC/AL facilities have a "standard" SCU (5 dementia care features).
3. Identify which facility level characteristics affect the likelihood that a facility has (1) a "substandard" SCU, and (2) a "standard" SCU.

2.1.3 Hypotheses

It is predicted that the majority of RC/ALs with SCUs will have all 5 SCU features. RC/ALs with SCUs will be large, for-profit, and admit individuals with cognitive impairment. Also, facility size and admission features will affect the likelihood of whether an SCU is "standard" (5 dementia care features present) or "substandard" (0-4 dementia care features present).

2.2 Methods

Descriptive statistics, pattern variable methodology, and multivariate analyses were used in this observational, cross sectional study. These methods were used to explore how many and what types of RC/ALs provided all, some, or none of the SCU features of dementia care in their facilities. Logistic regression was used to determine

what facility characteristics affect the likelihood that an RC/AL will claim to have an SCU but does not offer all five of the minimum dementia care features ("substandard" SCU). This model is then compared to a logistic regression used to determine the facility characteristics that affect the likelihood that facilities that claim to have an SCU have all five of the minimum features and are in fact a true, "standard" SCU.

2.2.1 Sample

Data from the 2010 National Survey of Residential Care Facilities (NSRCF) were used. NSRCF facility and individual data were collected by the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics (NCHS), Division of Health Care Statistics. NSRCF residential care facilities had to be registered, licensed, listed, certified, or otherwise regulated by the state; have four or more licensed, certified, or registered beds; have at least one resident currently living in the facility; and provide room and board with at least two meals a day, around the clock on-site supervision, and help with personal care or health related services.

The national survey used a stratified two-stage probability sample design with interviews conducted in 2,302 facilities. The data were collected using interviews with facility administrators and other staff members. Residents were not interviewed during this survey.

The 2010 NSRCF has two publicly available data sets. A facility level data set and an individual (resident) level data set. Unfortunately, these data sets cannot be combined. This study uses the facility level data set. Each RC/AL is one unit of analysis in this study.

2.2.2 Measures

Dependent Variable(s) – The main dependent variable of interest in this study was whether the unit is an SCU or not. SCU was measured as a dichotomous variable and was answered as either "yes," SCU present in facility or "no," not present in the RC/AL facility.

Five special care unit, dementia features were analyzed and are recognized by the NSRCF as the minimum basic characteristics of an SCU. The features are: (1) locked exit doors, (2) personal monitoring devices, (3) an enclosed courtyard, (4) higher staff-to-resident ratios compared to other units, and (5) specially trained staff. Each of these SCU features were measured as dichotomous variables and were answered as either "yes," present or "no," not present.

RC/AL SCUs were then separated into 2 groups: "standard" SCUs (five of the minimum dementia care features provided) and "substandard" SCUs (0-4 of the minimum dementia care features provided).

Independent Variable(s) – The administrators and staff of each RC/AL answered NSRCF questions concerning the characteristics of each facility. The characteristics explored include: size, ownership, chain, less than 10 years of operation, metropolitan area, participation in Medicaid, purposely built as an RC/AL, use of physical restraints, regular use of drugs to control behavior (chemical restraints), and admissions criteria (admit people who: cannot evacuate without help, have moderate to severe cognitive impairment, exhibit problem behavior, and need nursing home services regularly). Each of these independent variables was measured as dichotomous variables ("no" coded as 0

and “yes” coded as 1) except for size. Size was measured as small (4-10 beds), medium (11-25), and large (over 26 beds).

2.2.3 Analyses

The dementia care features of SCUs and these units’ corresponding facility characteristics were analyzed using STATA 13 statistical software. Descriptive statistics, pattern variable methodology, and multivariate analyses were used in this cross sectional study. These methods were used to explore how many and what types of RC/ALs provided all, some, or none of the SCU features of dementia care in their facilities.

Logistic regression and survey adjustment methodology were used to determine what facility characteristics affect the likelihood that an RC/AL will claim to have an SCU but does not offer the five minimum dementia care features (“substandard” SCU). This model was then compared to a logistic regression used to determine the facility characteristics that affect the likelihood that facilities that claim to have an SCU have all five of the minimum features and are in fact a true, “standard” SCU.

2.3 Results

Table 1 shows facility characteristics across all RC/ALs, RC/ALs with SCUs, and RC/ALs without SCUs. The percentages displayed in this table’s columns show that facilities with SCUs tend to be larger, for-profit, part of a chain, located in a metropolitan area, and purposely built as an RC/AL. These facilities with SCUs are more likely to use physical restraints (13%) and drugs to control behavior or reduce agitation (81%) than facilities without SCUs (12% and 64% respectively).

Statistical significance was measured using Pearson Chi-Squared test statistic for difference in proportions. The null hypothesis states that the SCU proportion is equal to the non-SCU proportion. The alternate hypothesis states that the SCU proportion is not equal to the non-SCU proportion. Statistics with a p-value less than 0.05 reject the null hypothesis and are starred (*).

Table 2 compares the frequency and percent of facilities that report the presence of each of the five SCU features. Out of the 485 facilities with SCUs, the majority report having locked doors, enclosed courtyards, higher staff to resident ratio, and specially trained staff. However, only 36% of the 485 facilities have personal monitoring devices for residents living in SCUs.

Table 1 Percent (%) of facility characteristics across RC/ALs without and with SCUs (N = 2,302) * p-value less than 0.05

Facility Characteristics		All RC/ALs (N=2,302)	RC/ALs without SCUs (N=1,816)	RC/ALs with SCUs (N=485)
Variables	**Categories**			
Size	Small (4-10 beds)	27.1	32.7*	6.6*
	Medium (11-25)	28.4	31.6*	16.5*
	Large (Over 26)	44.4	35.7*	76.9*
Ownership	For-profit	77.1	76.7	78.8
Chain	Yes	42.3	37.5*	60.4*
Years of operation over 10 years	Yes	36.4	63.4	64.3
Located in metropolitan area	Yes	73.2	71.2*	82.7*
Participate in Medicaid	Yes	48.8	51.7*	37.8*
Purposely built as RC/AL	Yes	58.6	51.9*	84.1*
Uses physical restraints	Yes	11.9	11.7	12.8
Regularly uses drugs to control behavior or to reduce agitation	Yes	68.0	64.4*	81.4*
Admissions Criteria: Admit people who…	Cannot evacuate without help	58.7	53.4*	77.4*
	Have moderate to severe cognitive impairment	55.6	46.2*	87.9*
	Exhibit problem behavior (wandering, outbursts, etc.)	38.7	31.3*	70.3*
	Need nursing home services regularly	16.5	17.8*	11.7*

Table 2 Frequency and percent (%) of facilities with each of the five features (N = 485)

Feature	Yes		No	
	Frequency	**Percent (%)**	**Frequency**	**Percent (%)**
Locked doors	375	77.3	110	22.7
Personal monitoring device	175	36.1	310	63.9
Enclosed courtyard	408	84.1	77	15.9
Higher staff to resident ratio	392	80.8	93	19.2
Specially trained staff	435	89.7	50	10.3

The frequency and percent of the most common combinations of the five SCU features are displayed in Table 3. Around 22% of RC/ALs with SCUs have all five of the dementia care features. Approximately 35% of facilities have all features except personal monitoring devices. Every combination of features is seen in this sample of RC/ALs with facilities reporting an enclosed courtyard, higher staff to resident ratio, and specially trained staff tallying at over 6%. It is important to note that over 1% of facilities that claim to have an SCU have none of the five dementia care features.

Table 3 Frequency and percent (%) of the most common combinations of SCU features (N = 485)

Locked doors	Personal monitoring devices	Enclosed courtyard	Higher staff to resident ratio	Specially trained staff	Frequency	Percent (%)
X		X	X	X	169	34.9
X	X	X	X	X	108	22.3
		X	X	X	31	6.4
X		X		X	29	6.0

Table 4 shows the frequency and percent of facilities with 0-2, 3, 4, or 5 SCU features. Approximately 42% of facilities that have an SCU have some combination of 4 of the 5 dementia care features. Around 13% of facilities that claim to have an SCU have 0 to 2 of the SCU features.

Table 4 Frequency and percent (%) of facilities with 0-2, 3, 4, or 5 SCU features (N = 485)

Number of SCU Features	Frequency	Percent (%)	Cumulative Percent (%)
0-2	63	13.0	13.0
3	109	22.5	35.5
4	205	42.3	77.7
5	108	22.3	100.0

The results of the first multivariate logistic regression appear in table 5. This model shows which facility characteristics affect the likelihood that a facility will claim

to have an SCU but does not provide the five minimum dementia care features. Holding all other variables constant, the odds of a facility having a "substandard" SCU increase when the facility increases in size and when the facility has admission criteria including: cannot evacuate without help, moderate to severe cognitive impairment, and exhibit problem behavior. These variables are statistically significant at the p-value level of 0.05.

It can be interpreted that in table 5, the odds of having a "substandard" SCU for large facilities is 5.55 times the odds of having a "substandard" SCU for small facilities, holding other variables constant. In other words, in large facilities, the odds of having a "substandard" SCU increase by 455% when compared to small facilities. The odds of having a "substandard" SCU for facilities who regularly use drugs to control behavior is 1.60 times the odds of having a "substandard" SCU for facilities who do NOT regularly use drugs to control behavior, holding all other variables in the model constant. For facilities that regularly use chemical restraints, the odds of having a "substandard" SCU increase by 60% when compared to facilities that do not use chemical restraints regularly to control behavior or to reduce agitation.

Table 5 Logistic regression – Facility characteristics that affect the likelihood that a facility has a "substandard" SCU (0-4 SCU features present) * p-value less than 0.05

Facility Characteristics		Odds Ratio	95% CI
Size	Medium (11-25)	2.30*	1.26-4.20
	Large (Over 26 beds)	5.55*	2.88-10.69
Private, for-profit ownership		1.05	0.69-1.60
Chain		1.08	0.71-1.66
Years of operation over 10 years		0.74	0.48-1.13
Located in metropolitan area (MSA)		1.63	0.86-3.08
Participate in Medicaid		0.70	0.46-1.06
Purposely built as RC/AL		1.34	0.78-2.29
Uses physical restraints		0.66	0.36-1.22
Regularly uses drugs to control behavior or to reduce agitation		1.60*	1.01-2.54
Admission: Cannot evacuate without help		1.61*	1.00-2.59
Admission: Mod/severe cognitive impairment		3.56*	1.81-6.98
Admission: Exhibit problem behavior		1.87*	1.14-3.05
Admission: Needs skilled nursing home services		0.73	0.41-1.32

Table 6 shows the logistic regression modeling the facility characteristics that affect the likelihood that facilities that claim to have an SCU have all five SCU features (a true, "standard" SCU). Holding all other variables constant, the odds of having a "standard" SCU for large facilities is 16.41 times the odds of having a "standard" SCU for small facilities. In other words, in large facilities compared to small facilities, the odds of having a "standard" SCU increase by 1,541%. In facilities purposely built as an RC/AL compared to facilities originally built with a different purpose, the odds of having a "standard" SCU increase by 550%. In facilities who admit individuals with moderate to severe cognitive impairment (compared to facilities that do NOT admit individuals with moderate to severe cognitive impairment), the odds of having a

"standard" SCU increase by 1,687%. For RC/ALs that participate in Medicaid, the odds of having a "standard" SCU decrease by 49% when compared to RC/ALs that do not participate in Medicaid.

Table 6 Logistic regression – Facility characteristics that affect the likelihood that a facility has a "standard" SCU (5 features present) * p-value less than 0.05

Facility Characteristics		**Odds Ratio**	**95% CI**
Size	Medium (11-25)	6.15	0.93-40.90
	Large (Over 26 beds)	16.41*	2.64-101.9
Private, for-profit ownership		0.75	0.37-1.54
Chain		1.23	0.66-2.29
Years of operation over 10 years		0.83	0.40-1.69
Located in metropolitan area (MSA)		0.58	0.22-1.52
Participate in Medicaid		0.51*	0.28-0.95
Purposely built as RC/AL		6.50*	1.25-33.99
Uses physical restraints		0.71	0.28-1.79
Regularly uses drugs to control behavior or to reduce agitation		0.90	0.40-2.04
Admission: Cannot evacuate without help		1.08	0.51-2.32
Admission: Mod/severe cognitive impairment		17.87*	4.26-74.92
Admission: Exhibit problem behavior		4.24*	1.83-9.80
Admission: Needs skilled nursing home services		0.75	0.32-1.77

2.4 Discussion

These results indicate that facilities with SCUs slightly differ from RC/ALs without SCUs in terms of facility characteristics. Although a fifth of all RC/ALs claim to have an SCU, only 22% of those that claim to have an SCU have all five minimum features and over 1% of those that claim to have an SCU have none of the features. A

concrete, legal definition is needed in order to identify which facilities are providing the minimum standard of memory care.

The logistic regressions show that for facilities that regularly use chemical restraints, the odds of having a "substandard" SCU increase by 60% when compared to facilities that do not use chemical restraints regularly to control behavior or to reduce agitation.

Current research reports that the adverse effects of chemical restraints or antipsychotic drugs used to control behavior or to reduce agitation outweighs the advantages of this treatment in patients living with Alzheimer's disease (Schneider et al., 2006). In fact, the use of atypical antipsychotic drugs to control behavior in people with dementia increases the risk of death compared to dementia patients treated with placebos (Schneider, Dagerman, & Insel, 2005). Similarly, the use of conventional antipsychotic drug treatment has a risk of death that is comparable and possibly higher than the atypical antipsychotic drug treatment risk of death (Schneeweiss, Setoguchi, Brookhart, Dormuth, & Wang, 2007).

Similarly, research concerning physical restraint use in NHs report that use of physical restraints is an extremely negative practice that significantly impacts quality of care for the worse (Castle & Mor, 1998). The Phase 2 Alzheimer's Association Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes recommend physical restraint-free care (Reed & Tilly, 2008).

Despite these recommendations and research findings, restraint use is still present with 13% of RC/ALs with SCUs reporting the use of physical restraints and a staggering

81% of RC/ALs with SCUs reporting the use of chemical restraints. This presence of physical and chemical restraints in SCUs indicates the need for future research on the quality of life and quality of care of residents in these facilities with SCUs.

With the increasing need for dementia specific care and the social and political push away from NHs and, subsequently, toward RC/ALs, it is important to understand the nature and characteristics of SCUs. According to these analyses and the NSRCF survey sample, approximately 20% of RC/ALs have an SCU and a little over 20% of these RC/ALs have an actual SCU that provides all five features of dementia care. This means that in this country, less than 5% of RC/ALs have a "standard" SCU. There are not enough facilities with the five minimum SCU criteria to meet the growing demand for memory care in long-term care facilities.

This study is not without its limitations. First, statistics for facilities with SCUs are comprehensive and do not provide a look at the characteristics specific to the unit of interest. For example, the percent of residents that receive medication administration cannot be isolated to just within an SCU. The percentage is taken for the entire facility that reports having an SCU. Second, the NSRCF data has been cleaned and categorized to protect the identity of the residents and of the facilities that participated in the study. Because of this, the relationship between facility characteristics and having an SCU may be blurred and underestimated.

Despite these limitations, the results show that less than 5% of RC/ALs are prepared to take good care of those with Alzheimer's and other forms of dementia. The growing demand for memory care must be matched by a supply of facilities that truly

provide the minimum standard of dementia specific care. The lack of these types of facilities and the absence of a legal definition for SCUs leaves this vulnerable population at risk for substandard care and potential exploitation.

The lack of licensure or a concrete definition leads to variability between RC/ALs that claim to have an SCU. Facilities may advertise these SCUs as a model of care for persons with dementia; however, there is no definition or standard of care that these facilities can hold themselves to. In essence, with no accountability, RC/AL SCUs can call themselves a model of care, when, in fact, these units could be providing the exact same or fewer services of a traditional RC/AL unit. The variability of characteristics between the three SCUs in this study highlights this problem and emphasizes the need for a legal definition of SCUs.

With this research, policy makers can move toward developing a concrete, legal definition of an SCU. Also, long-term care stakeholders can evaluate whether there is a need to provide additional resources to make SCUs more readily accessible to families of individuals in need of dementia specific care. Overall, it is important to have more information publicly available and accessible concerning what constitutes an SCU and how an individual may go about entering an RC/AL SCU.

This research is one of the first steps toward exploring this form of care for cognitively impaired older individuals. Future research is needed to better understand the complexities surrounding SCUs and how to best provide care for residents that reside within these SCUs.

3. ALZHEIMER'S SPECIAL CARE UNIT RESIDENTS LIVING IN RESIDENTIAL CARE AND ASSISTED LIVING FACILITIES: COMPARING SCU TO NON-SCU RESIDENTS ACROSS RESIDENT CHARACTERISTICS, FALLS, ER VISITS, AND HOSPITAL STAYS

Objectives(s): *To compare Residential Care/Assisted Living (RC/AL) residents living in traditional units (non-SCUs) and residents living in Alzheimer's disease/dementia specific Special Care Units (SCUs).*

Design and Methods: *Descriptive statistics and bivariate analyses were used in this cross sectional study of 2010 National Survey of Residential Care Facilities (NSRCF) data. Resident characteristics, including demographic and health-related, facility characteristics, falls, ER use, and hospital stays were described and analyzed across type of RC/AL unit, including traditional and SCU. Bivariate analyses were used to find the association between resident/facility characteristics and whether or not the resident lives in an SCU.*

Results: *The average resident in an RC/AL is over the age of 85, female, white/Caucasian, has excellent English proficiency, widowed, and has resided in the facility for over a year. Residents in SCUs have similar demographic characteristics as residents in traditional, non-SCU, units; however, these two groups differ in health-related characteristics with residents living in SCUs reporting poorer overall health, having lower participation in Medicaid, and having much higher rates of urinary/bowel incontinence and mental health issues, including Alzheimer's disease, confusion, and*

memory problems. Residents living in SCUs had higher percentages of falls resulting in a hip fracture or other injury compared to residents living in traditional, non-SCUs. *Disucssion/Conclusion:* *Policies are needed to address these issues in SCUs and to better protect residents living in RC/ALs.*

3.1 Introduction

In 2015, over 5 million individuals over the age of 65 were living with Alzheimer's disease or other forms of dementia (Alzheimer's Association, 2015). This number is expected to reach over 7 million by the year 2025 (Alzheimer's Association, 2015). Out of the top 10 causes of death in the United States, Alzheimer's disease is the only cause of death that has no known cure, method of prevention, or treatment to slow the progression of disease (Alzheimer's Association, 2015). The number of deaths caused by this disease has increased by over 71% in the past decade (Alzheimer's Association, 2015). Discussion and exploration of the social, political, and economic implications of this disease and the care modalities provided for individuals living with Alzheimer's disease or other dementias are of incredible importance as the population of people affected by Alzheimer's disease and dementia grows.

Over the past few years, the Residential Care and Assisted Living Facility (RC/AL) industry has grown rapidly, housing and providing care to residents in approximately 30,000 facilities and over 900,000 beds nationwide in 2010 (Park-Lee et al., 2011). Some of these facilities house Special Care Units (SCUs) to provide specialized care for individuals living with Alzheimer's disease and other dementias. Not much is known about SCUs and the residents who reside in these specialized modalities of care. The purpose of this study is to compare Residential Care/Assisted Living (RC/AL) residents living in traditional units (non-SCUs) and residents living in Alzheimer's disease/dementia specific Special Care Units (SCUs) across resident

demographics, health-related characteristics, facility characteristics, falls, ER use, and hospital stays (non-ER).

3.1.1 Background

While Alzheimer's disease is not the only cause of dementia and cognitive impairment among individuals, it is the leading cause for mental functional decline (Glenner, 1982). The prevalence of this disease is rapidly growing in the United States. In 2010, almost 5 million Americans over the age of 65, and of those 1.8 million over the age of 85, were living with Alzheimer's disease or other dementias (Hebert, Weuve, Scherr, & Evans, 2013). This number of people living with Alzheimer's disease and dementia is expected to increase to 13.8 million, with approximately 7 million of these individuals over the age of 85, by 2050 (Hebert et al., 2013).

Estimates of the prevalence of Alzheimer's disease and other dementias in the RC/AL setting vary across studies and methods of detecting dementias. It is estimated that 23-42% of RC/AL residents have moderate to severe cognitive impairment or diagnosable dementia (Zimmerman et al., 2003). A study using the 2010 National Survey of Residential Facilities (NSRCF) reports that 70% of RC/AL residents have some form of cognitive impairment with 19% of RC/AL residents living with severe cognitive impairment (Zimmerman, Sloane, & Reed, 2014). Other studies, such as one in Maryland found two thirds of all RC/AL residents have dementia, using psychiatric examinations and case findings (Rosenblatt et al., 2004).

Despite these differences, the overall finding is clear: a substantial and growing population of RC/AL residents suffers from some type of cognitive impairment, most

commonly Alzheimer's disease or other dementias. These percentages are increasing as more and more residents enter the RC/AL market and as life expectancy increases across the United States.

Each year, 30-60% of all people, 65 years or older, experience a fall (Rubenstein, 2006). Of these falls, it is reported that 10-20% result in serious injury, hospitalization, and/or death (Rubenstein, 2006). Two-thirds of unintentional injuries causing death, the 5th leading cause of death among older adults, are from falls (Kannus, Parkkari, Niemi, & Palvanen, 2005). Residents living in long-term care facilities are more likely to experience a fall resulting in a serious injury, compared to community dwelling, older individuals (Rubenstein, 2006). Similar to the risk of falling, the fear of falling is widespread among residents living in long-term care facilities (over 50% of residents) and this fear has been linked to depression, poor quality of life, and other negative outcomes (Lach & Parsons, 2013). With this pervasive fear of and presence of falls in older individuals, it is imperative to understand the risk factors and situations surrounding this issue.

While the relationship between falls and a variety of risk factors, such as age, a previous fall, and comorbidities including osteoporosis, has been studied using many different statistical methods, falls among individuals living in an SCU have not been explored (Mitty, Mitty, & Flores, 2007).

3.1.2 Theoretical/Conceptual Framework

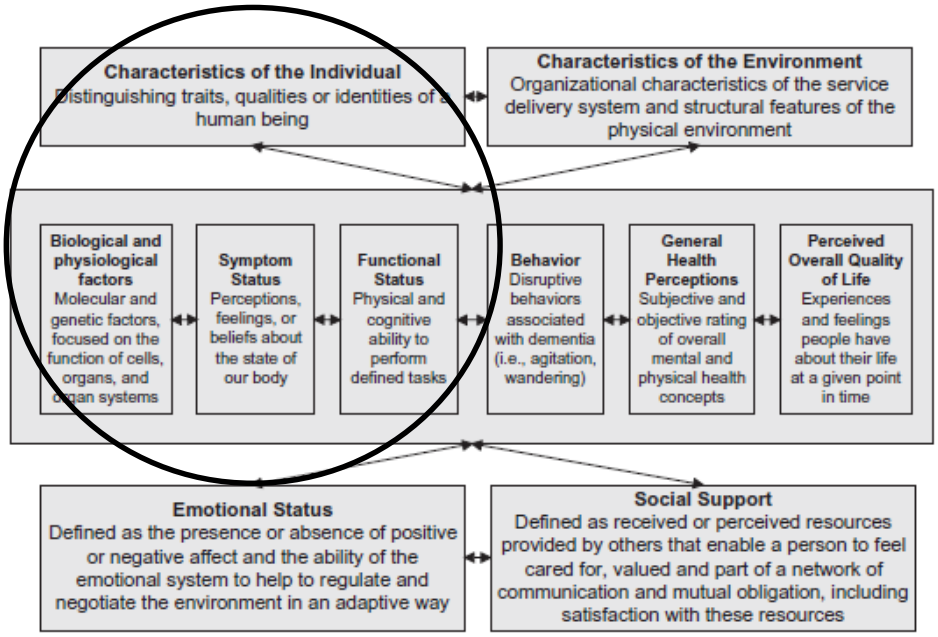

Figure 1. The long-term services and supports health-related quality of life conceptual model. As developed by Wilson and Cleary (1995) and adapted by Brod and colleagues (1999); with Patrick (1997).

Figure 3 Health-related quality of life (HRQoL) for older adults who receive long-term services and supports (LTSS) – 2nd Tier (Zubritsky et al., 2012)

With a health related quality of life model focused on long-term services and supports (HRQoL-LTSS), this study focuses on the characteristics of the individual. These analyses use individual, resident qualities and traits and focus on characteristics of the individual including: symptom status, functional status and the resident's physical and cognitive capabilities (Zubritsky et al., 2012).

3.1.3 Problem/Purpose

The purpose of this study is to compare Residential Care/Assisted Living (RC/AL) residents living in traditional units (non-SCUs) and residents living in

Alzheimer's disease/dementia specific Special Care Units (SCUs) across resident demographics, health-related characteristics, facility characteristics, falls, ER use, and hospital stays (non-ER). The study focuses on populations of cognitively impaired residents residing in RC/ALs. Very often these populations include residents with dementia and other diseases.

3.1.4 Specific Aims

1. Examine individual level characteristics of residents living in RC/AL SCUs and non-SCUs.
2. Compare SCU residents to non-SCU residents across: demographics, health related characteristics, facility characteristics, falls, ER use, and hospital stays (non-ER).

3.1.5 Hypotheses

It is predicted that RC/AL residents living in SCUs will differ from residents living in non-SCUs across resident demographics, health-related characteristics, falls, ER use, and hospital stays (non-ER).

3.2 Methods

Descriptive statistics and bivariate analyses were used in this cross sectional study of 2010 National Survey of Residential Care Facilities (NSRCF) data. Resident characteristics, including demographic and health-related, facility characteristics, falls, ER use, and hospital stays were described and analyzed across type of RC/AL unit, including traditional, non-SCU and SCU.

Bivariate analyses were used to find the association between resident/facility characteristics and whether or not the resident lives in an SCU.

3.2.1 Sample

Data from the 2010 National Survey of Residential Care Facilities (NSRCF) were used. NSRCF facility and individual data were collected by the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics (NCHS), Division of Health Care Statistics. NSRCF residential care facilities had to be registered, licensed, listed, certified, or otherwise regulated by the state; have four or more licensed, certified, or registered beds; have at least one resident currently living in the facility; and provide room and board with at least two meals a day, around the clock on-site supervision, and help with personal care or health related services.

The national survey used a stratified two-stage probability sample design with interviews conducted in 2,302 facilities. The data were collected using interviews with facility administrators and other staff members. Residents were not interviewed during this survey. The 2010 NSRCF has two publicly available data sets. A facility level data set and an individual (resident) level data set. This study uses the resident, individual level data set. Each RC/AL resident is one unit of analysis in this study.

3.2.2 Measures

Dependent Variable(s) – The main dependent variable of interest in this study is whether the resident lives in an SCU or not. SCU was measured as a dichotomous variable and was answered as either "yes," the resident lives in an SCU or "no," the

resident lives in a traditional, non-SCU setting. Each RC/AL resident is one unit of analysis.

Independent Variable(s) – The independent variables of interest in this study are: resident demographics, resident health related characteristics, facility characteristics, falls, ER use, and hospital stays (non-ER).

Resident demographic variables include: age, gender, race/ethnicity, English proficiency, education, marital status, length of stay (LOS), and Medicaid participation. Residents were separated into three groups for age: 18-64, 64-84, 85+ years of age. Gender was coded as a dichotomous variable with male = 0 and female = 1. The race/ethnicity variable had five groups: Hispanic/Latino, White/Caucasian, Black/African American, Asian, and other. English proficiency was measured as an ordinal variable with residents classified into six groups of English speaking proficiency: excellent, very well, well, fair, poor or not at all, and does not speak. Residents were split into two groups for education level: high school or less and college or more. Residents' marital status fell in one of five groups: married, divorced, legally separated, widowed, and never married. Residents who have lived in the RC/AL facility for less than a year were coded as a 0 for LOS while residents who have lived in the facility for over a year were coded as a 1. The Medicaid participation variable was coded as a dichotomous variable with residents participating in Medicaid receiving a 1 and all others receiving a 0.

Resident health related characteristics include: overall health, assistance with activities of daily living (ADLs), incontinence issues, mental health issues, confusion

problems, and memory problems. Overall health was coded as an ordinal variables with the following categories: excellent, very good, good, fair, poor. Eight separate ADLs are identified in the NSRCF database. These 8 ADLs include assistance with: transfers, walking, bathing/showering, dressing, eating, leaving the facility, using the toilet, and evacuating the facility. Assistance with ADLs was separated into two groups: resident needs assistance with less than five ADLs and resident needs assistance with five or more ADLs. Urinary incontinence and bowel incontinence were each coded as dichotomous variables. Residents with urinary incontinence issues were coded as a 1 and residents without urinary incontinence issues were coded as a 0.

Four mental health issues (Alzheimer's disease, depression, schizophrenia, and other mental health issue), confusion, short-term memory problems, and long-term memory problems were included as dichotomous variables (0 = not present, 1 = present). Confusion was coded as a 1 if the respondent answered the following question with "yes": Is [the resident] limited in any way because of difficulty remembering or because [the resident] experiences periods of confusion? Short term memory problem was coded as a 1 if the respondent answered the following question with "yes": During the last 7 days, has [the resident] given evidence of a problem with short-term memory, such as difficulty remembering what(he/she) had for breakfast or something you told (he/she) a few minutes earlier? Long term memory problem was coded as a 1 if the respondent answered the following question with "yes": During the last 7 days, has [the resident] given evidence of a problem with long-term memory, such as forgetting how old (he/she) is or forgetting that (he/she) was married.

RC/AL facility characteristics include: size, MSA, chain, and ownership. Residents lived in a small (4-10 beds), medium (11-25 beds), or large (>26 beds) facility. Residents living in a Metropolitan Statistical Area (MSA) were coded as 1 and residents living in a non-MSA RC/AL were coded as 0. Similarly, residents living in RC/AL facilities that belong to a chain were coded as 1 and residents living in a non-chain RC/AL were coded as 0. Residents were then separated into two groups: living in a private/for-profit facility or living in a public or private/not-for-profit facility.

The falls variable in this study is whether the RC/AL resident has had a fall resulting in a hip fracture or other injury in the past 12 months. This variable is a dichotomous variable and was answered as either "yes," the resident has had a fall in the past 12 months or "no," the resident has not had a fall in the past 12 months resulting in a hip fracture of other injury. ER use is whether the RC/AL resident has visited an ER in the past 12 months. This variable is a dichotomous variable and was answered as either "yes," the resident has visited an ER in the past 12 months or "no," the resident has not has not visited an ER in the past 12 months. Hospital stay (non-ER) is whether the RC/AL resident has spent the night in the hospital in the past 12 months. This variable is a dichotomous variable and was answered as either "yes," the resident has spent the night in a hospital in the past 12 months or "no," the resident has not spent the night in a hospital in the past 12 months.

3.2.3 Analyses

Descriptive statistics and bivariate analyses were used in this cross sectional study of 2010 National Survey of Residential Care Facilities (NSRCF) data. Resident

characteristics, including demographic and health-related, facility characteristics, falls, ER use, and hospital stays were described and analyzed across type of RC/AL unit, including traditional (non-SCU) and SCU. Bivariate analyses were used to find the association between resident/facility characteristics and whether or not the resident lives in an SCU. Statistical significance was measured using Pearson Chi-Squared test statistic for difference in proportions. The null hypothesis states that the percentage of SCU residents is equal to the percentage of non-SCU residents. The alternate hypothesis states that the SCU proportion is not equal to the non-SCU proportion. Statistics with a p-value less than 0.05 reject the null hypothesis and are starred (*).

3.3 Results

The average resident in an RC/AL is over the age of 85, female, white/Caucasian, has excellent English proficiency, widowed, and has resided in the facility for over a year. Residents in SCUs have similar demographic characteristics as residents in traditional, non-SCU, units; however, these two groups differ in health-related characteristics with residents living in SCUs reporting poorer overall health, having lower participation in Medicaid, and having much higher rates of urinary/bowel incontinence and mental health issues, including Alzheimer's disease, confusion, and memory problems. Residents living in SCUs had higher percentages of falls resulting in a hip fracture or other injury compared to residents living in traditional, non-SCUs.

Descriptive, demographic statistics are shown in table 7. These variables are shown in percentages and the columns to the right represent percentages out of all residents (N = 8,094), residents living in a traditional, non-SCU (N = 7,178), and

residents living in an SCU (N = 916). Approximately 11% of RC/AL residents live in an SCU and 89% do not live in an SCU.

The average resident in an RC/AL is over the age of 85, female, white/Caucasian, has excellent English proficiency, widowed, and has resided in the facility for over a year. When it comes to resident demographic characteristics, the distribution of proportions is somewhat similar for residents living in traditional, non-SCUs and for residents living in SCUs.

Resident demographic characteristics are composed of 8 different variables including: age, gender, race/ethnicity, English proficiency, education, marital status, length of stay (LOS), and whether or not the resident participates in Medicaid to fund their long-term care. According to the results below in table 7, approximately 57% of SCU residents are over the age of 85 and less than 3% are under the age of 65. The majority of all RC/AL residents are female (70%). The vast majority of residents are white/Caucasian (91% of all residents) with 94% of residents living in SCUs identifying with this race/ethnicity group. Many SCU residents are widowed (66%) or married (20%). 49% of residents living in SCUs and 62% of residents living in traditional, non-SCUs generally are "excellent" English speakers. The majority of all residents, both living and not living in an SCU, have resided in the RC/AL for over a year. Around 19% of all residents and 20% of residents living in traditional, non-SCUs participate in Medicaid while approximately 11% of residents living in an SCU use public, Medicaid funds.

Table 7 Descriptive and demographic characteristics of Residential Care/Assisted Living (RC/AL) residents living in traditional units (non-SCUs) and special care units (SCUs) * p-value<0.05 for difference in proportions test

Resident Characteristics		**All Residents (N = 8,094)**	**Residents in Traditional Unit (NOT SCU) (N = 7,178)**	**Residents in SCUs (N = 916)**
Variables	**Categories**	**%**	**%**	**%**
Age	18-64	10.5	11.8*	2.5*
	65-84	35.6	34.8*	40.7*
	85+	53.8	53.4*	56.9*
Gender	Female	69.6	69.5	70.5
Race/Ethnicity	Hispanic/Latino	2.9	2.9*	2.4*
	White/Caucasian	91.1	90.5*	94.4*
	Black/African American	4.3	4.7*	2.2*
	Asian	1.1	1.1*	0.7*
	Other	0.7	0.7*	0.3*
English Proficiency	Excellent	60.1	62.0*	48.7*
	Very Well	24.5	24.4*	24.7*
	Well	8.8	8.3*	12.1*
	Fair	3.1	2.6*	5.8*
	Poor or not at all	2.1	1.8*	3.9*
	Does not speak	1.5	0.9*	4.8*
Education	High School or less	59.4	60.4*	53.4*
	College or more	40.6	39.6*	46.6*
Marital Status	Married	13.1	12.0*	19.6*
	Divorced	9.5	9.7*	8.0*
	Legally Separated	0.6	0.7*	0.1*
	Widowed	63.2	62.7*	66.1*
	Never Married	13.7	14.9*	6.2*
Length of Stay	0-12 months	32.7	32.1*	36.1*
	1 + year	67.3	67.9*	63.9*
Medicaid	Present	18.9	20.3*	10.5*

Table 8 shows resident health-related characteristics of RC/AL residents living in traditional, non-SCUs and RC/AL residents living in SCUs. These variables are shown in percentages and the columns to the right represent percentages out of all residents (N = 8,094), residents living in a traditional, non-SCU (N = 7,178), and residents living in an SCU (N = 916).

According to table 8 below, over 16% of residents living in SCUs report "poor" overall health and around 33% of SCU residents report "fair" overall health. Of those residents who live in traditional, non-SCUs, only 9% report "poor" overall health and 31% of non-SCU residents report "fair" overall health. Approximately 44% of residents living in SCUs require assistance with five or more ADLs. This percentage is much lower for non-SCU residents with 25% requiring assistance with five or more ADLs. Around 67% of SCU residents have issues with urinary incontinence and 45% of SCU residents have issues with bowel incontinence. Again, these percentages go down in traditional, non-SCU, residents with 25% and 32% of urinary and bowel incontinence issues, respectively. An understandable 95% of SCU residents have been diagnosed with Alzheimer's disease while 34% of non-SCU residents are living with Alzheimer's disease. Over 94% of SCU residents and 41% of non-SCU residents have problems with confusion. Of those residents living in SCUs, 92% have short-term memory problems and 79% have long-term memory problems. Of those residents living in traditional units (non-SCU), 39% have short-term memory problems and 20% have long-term memory problems.

Table 8 Resident health-related characteristics of Residential Care/Assisted Living (RC/AL) residents living in traditional units (non-SCUs) and special care units (SCUs)
* p-value<0.05 for difference in proportions test

Resident Characteristics		**All Residents (N = 8,094)**	**Residents in Traditional Unit (NOT SCU) (N = 7,178)**	**Residents in SCUs (N = 916)**
Variables	**Categories**	**%**	**%**	**%**
Overall Health	Excellent	4.9	5.2*	3.0*
	Very Good	15.7	16.3*	12.1*
	Good	37.5	37.9*	35.4*
	Fair	31.5	31.3*	33.2*
	Poor	10.4	9.4*	16.3*
ADLs	>=5 (out of 8)	26.9	24.8*	43.6*
Incontinence	Urinary	37.1	32.3*	66.9*
	Bowel	20.1	16.1*	44.8*
Mental Health Issue	Alzheimer's Disease	42.1	33.6*	94.9*
	Depression	27.6	27.6	27.3
	Schizophrenia	7.6	8.1*	4.7*
	Other	11.8	12.4*	7.6*
Confusion	Present	48.8	41.4*	94.2*
Memory Problems	Short Term	46.2	38.7*	92.4*
	Long Term	28.2	20.0*	79.1*

Table 9 displays facility characteristics across RC/AL setting. Approximately 61% of SCU residents and 51% of non-SCU residents live in a large RC/AL facility with over 26 beds. The majority of all RC/AL residents live in a Metropolitan Statistical Area with 89% of SCU residents and 77% of non-SCU residents living in these urban areas. 69% of SCU residents and 54% if non-SCU residents live in an RC/AL that belongs to a chain (chain owns one or more facility). Finally, most SCU residents (82%) and non-SCU residents (74%) live in an RC/AL that is private and for-profit.

Table 9 Facility characteristics of Residential Care/Assisted Living (RC/AL) residents living in traditional units (non-SCUs) and special care units (SCUs) * p-value<0.05 for difference in proportions test

Facility Characteristics		**All Residents (N = 8,094)**	**Residents in Traditional Unit (NOT SCU) (N = 7,178)**	**Residents in SCUs (N = 916)**
Variables	**Categories**	**%**	**%**	**%**
Size	Small (4-10 beds)	10.3	11.3*	4.0*
	Medium (11-25)	9.1	9.3*	7.9*
	Large (>26)	52.1	50.7*	60.7*
MSA	Non-MSA	21.8	23.5*	11.5*
	MSA	78.2	76.5*	88.5*
Chain	Not a chain	44.0	46.1*	30.7*
	One or more facility	56.0	53.9*	69.3*
Ownership	Private, for-profit	74.9	73.7*	81.8*
	Public or private, not-for-profit	25.1	26.3*	18.2*

Table 10 shows falls, ER use, and non-ER hospital stays for RC/AL residents living in SCUs and RC/AL residents living in non-SCUs. Out of all residents living in an RC/AL, approximately 14% have experienced a fall resulting in a hip fracture or other injury in the past 12 months. For residents living in an SCU, this percentage is higher at over 20%. For residents who do not live in an SCU, about 13% have experienced a fall in the past 12 months. ER use was consistent across each RC/AL setting with approximately 33% of residents making an ER visit in the past 12 months. Around 20% of SCU residents and 23% of non-SCU residents spent the night in a hospital (non-ER admission) in the past 12 months.

Table 10 Resident health-related characteristics of Residential Care/Assisted Living (RC/AL) residents living in traditional units (non-SCUs) and special care units (SCUs) * p-value<0.05 for difference in proportions test

Resident Characteristics		**All Residents (N = 8,094)**	**Residents in Traditional Unit (NOT SCU) (N = 7,178)**	**Residents in SCUs (N = 916)**
Variables	**Categories**	**%**	**%**	**%**
Falls	Fall resulting in hip fracture or other injury in past 12 months	13.8	13.0*	20.4*
ER Use	Visit in the past 12 months	33.1	33.1	33.5
Hospital Stay (non-ER)	Spent night in hospital in the past 12 months	22.9	23.3*	20.0*
Hospital Stay (non-ER)	0 nights	67.0	67.1	66.6
	1 night	19.4	19.2	21.0
	2 nights	8.0	8.1	6.7
	3 or more nights	5.7	5.7	5.8

3.4 Discussion

These results indicate that residents in SCUs have similar demographic characteristics as residents in traditional, non-SCUs; however, these two groups differ in health-related characteristics with residents living in SCUs reporting poorer overall health, having lower participation in Medicaid, and having much higher rates of urinary incontinence, bowel incontinence, confusion issues, memory problems, and mental health issues/diagnoses, including Alzheimer's disease. Residents living in SCUs had higher percentages of falls resulting in a hip fracture or other injury compared to residents living in traditional, non-SCUs.

According to the Assessing Care of Vulnerable Elders (ACOVE) Project, experiencing a fall is a tested, research supported, quality indicator measure used to evaluate quality of care (Wenger, Roth, & Shekelle, 2007). As an indicator of quality of care, it is important to understand falls and factors associated with this measure. Falls in addition to mobility issues are one of many measures that indicate poor quality of care in medical settings including RC/ALs (Wenger, Roth, & Shekelle, 2007).

These results show that a higher percentage of residents living in SCUs have suffered a fall resulting in hip fracture or other injury in the past 12 months compared to non-SCU resident percentages. This finding indicates that while RC/ALs may advertise SCUs as a better model of care for people living with dementia, the quality of care received in SCUs may be deficient with a higher percentage of SCU residents experiencing a dangerous fall episode compared to the percentage of non-SCU residents.

Many SCUs tend to require private payments based on a flat rate or point system. Less than 11% of SCU residents participate in and utilize Medicare and Medicaid insurance plans (table 8). National estimates of RC/ALs report residents living in non-SCUs pay $2,818 per month for a single room while residents living in SCUs pay $3,843 monthly for a single occupancy room (Zimmerman, Sloane, & Reed, 2014). The predominately private pay nature of RC/ALs with SCUs and the, on average, $1,000 increase in cost per month for residents living in SCUs must be considered by LTSS consumers.

This study is not without its limitations. First, the NSRCF data has been cleaned and categorized to protect the identity of the residents and of the facilities that

participated in the study. Because of this, the breakdown of categories may be oversimplifying the relationship between the studied variables.

Second, the 2010 NSRCF gathered data on residents by interviewing facility staff members. The data provided is self-reported by the facility rather than individual residents. This data source may not be the most accurate account of individual characteristics and is a limitation that must be considered when interpreting results in this study.

Despite these limitations, this study reports that SCU residents are different from non-SCU residents when it comes to health-related characteristics and resident outcomes, including experiencing a fall resulting in a hip fracture or other injury. Currently, RC/AL SCUs have no concrete, legal definition to make services/care practices provided in SCUs transparent. This lack of transparency and consequent variability across SCUs may be allowing facilities to provided subpar care. Policies are needed to address this lack of an SCU definition and the lack of protections afforded to vulnerable individuals living in SCUs with Alzheimer's disease and other forms of dementia.

This research is one of the first steps toward exploring this form of care for cognitively impaired older individuals living in RC/ALs. Future research is needed to better understand the complexities surrounding SCUs and how to best provide care for residents that reside within these SCUs. In particular, research is needed concerning the relationship between a resident living in an SCU or a non-SCU and quality of care outcome measures.

4. BEHAVIORAL ISSUES IN ALZHEIMER'S DISEASE SPECIAL CARE UNIT RESIDENTS LIVING IN RESIDENTIAL CARE AND ASSISTED LIVING FACILITIES

Objective(s): *To study the presence of behavioral issues exhibited by Residential Care/ Assisted Living (RC/AL) residents living in traditional units (non-SCUs) and Alzheimer's disease/dementia specific Special Care Units (SCUs).*

Design and Methods: *Descriptive statistics and multivariate analyses were used in this cross sectional study of 2010 National Survey of Residential Care Facilities (NSRCF) data. Resident characteristics, including demographic and health-related, facility characteristics, and behavioral issues were described and analyzed across type of RC/AL unit, including traditional and SCU. Ten behaviors measured by the 2010 NSRCF were grouped into four literature supported subgroups: aggressive, physical (non-aggressive), verbal, and resistant to care. Ordered logit regressions were used to find the association between the four behavioral subgroups and whether or not the resident lives in an SCU, controlling for characteristics of residents and facilities.*

Results: *Residents living in SCUs had higher percentages of behavior issues in each of the four behavior subgroups, compared to residents living in traditional, non-SCUs. The multivariate analyses show that there is a positive association between living in an SCU and each of the four behavioral issue subgroups, controlling for demographic and health-related characteristics of residents.*

Discussion/Conclusion: The presence of behavioral issues among residents, particularly residents living in SCUs, indicates the need for additional mental health services provided within facilities. The current state of long term supports and services (LTSS) provided within RC/ALs may not be equipped to serve the rates of behavioral issues seen in residents. These behavioral issues may increase staff exposure to workplace violence and influence the risk of staff-to-resident or resident-to-resident abuse. Policies are needed to address these issues in SCUs and to better protect both residents living in RC/ALs as well as the staff providing care in this LTSS setting.

4.1 Introduction

Behavioral issues and psychiatric symptoms are common among individuals living with dementia (Savva, Zaccai, Matthews, Davidson, McKeith, & Brayne, 2009). These behavioral issues can not only complicate medical management and assessment but also affect the quality of life of both individuals living with dementia and the caregivers of these individuals (Cohen-Mansfield, Marx, & Rosenthal, 1989). Recently, there has been a move away from identifying these behavioral issues as simply disease symptoms or problems but rather as indications of unidentified complications or unmet needs that an individual is unable to communicate (Brod, Stewart, Sands, & Walton, 1999; Cohen-Mansfield, 2001; Gruber-Baldini, Boustani, Sloane, & Zimmerman, 2004).

While these behavioral issues have been studied in several settings including nursing homes and traditional RC/ALs, these issues have not been explored in RC/AL SCUs. The objectives of this study are to study and to compare the presence of behavioral issues, including aggressive, physical (non-aggressive), verbal, and resistant to care behavioral issues, exhibited by RC/AL residents living in traditional, non-SCUs and Alzheimer's disease or dementia specific SCUs.

4.1.1 Background

In a stratified random sample of Florida, Maryland, New Jersey, and North Carolina RC/ALs, researchers found that "approximately one-third (34%) of RC/AL residents exhibited one or more behavioral symptoms at least once a week" with 13% of residents displaying aggressive behavior, 20% displaying physical, non-aggressive behavior, 22% displaying verbal symptoms, and 13% of residents resisting care (Gruber-

Baldini, Boustani, Sloane, & Zimmerman, 2004, p. 1610). Of all the residents included in the study, 48% had a dementia diagnosis and 53% were currently taking one or more psychotropic medications, including neuroleptics, antidepressants, and hypnotics (Gruber-Baldini, Boustani, Sloane, & Zimmerman, 2004). With the high prevalence of behavioral issues seen in RC/ALs across four states, there is a need to study this issue at the national level.

4.1.2 Theoretical/Conceptual Framework

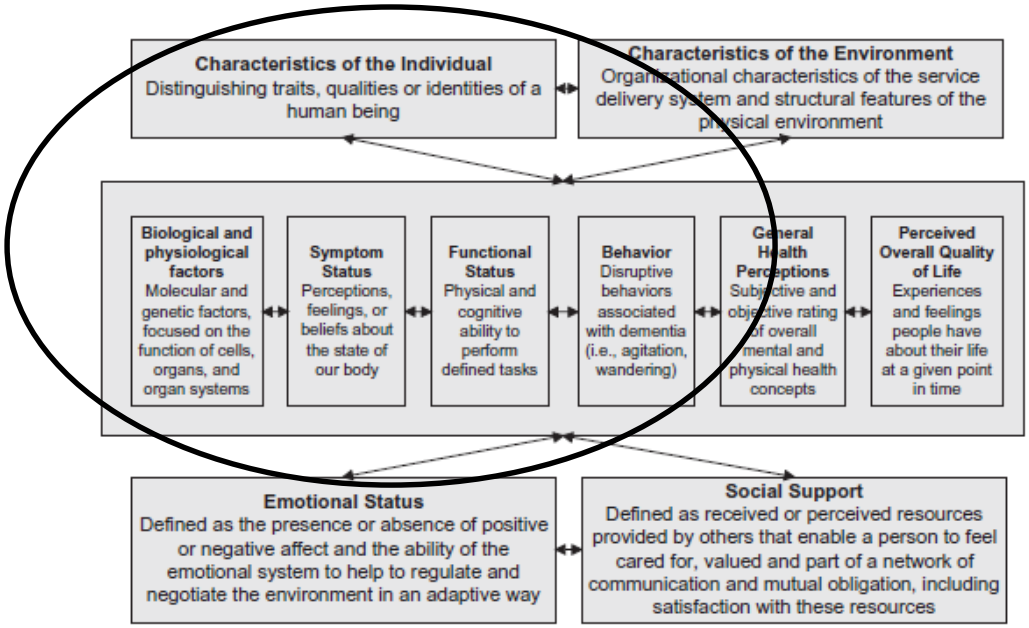

Figure 1. The long-term services and supports health-related quality of life conceptual model. As developed by Wilson and Cleary (1995) and adapted by Brod and colleagues (1999); with Patrick (1997).

Figure 4 Health-related quality of life (HRQoL) for older adults who receive long-term services and supports (LTSS) – 3rd Tier (Zubritsky et al., 2012)

This study focused on the characteristics of the individual while using the long-term supports and services health-related quality of life model. These analyses used individual, resident qualities and traits and focus on characteristics of the individual including: symptom status, functional status, the resident's physical and cognitive capabilities, and behavioral issues (Zubritsky et al., 2012).

4.1.3 Problem/Purpose

The purpose of this study is to study the presence of behavioral issues, including aggressive, physical (non-aggressive), verbal, and resistant to care behavioral issues, exhibited by RC/AL residents living in traditional, non-SCUs and Alzheimer's disease/dementia specific SCUs.

4.1.4 Specific Aims

1. Identify, categorize, and study behavioral symptoms exhibited by RC/AL residents living in SCUs and traditional, non-SCUs.
2. Find the association between living in an SCU and the four subgroups of behavioral issues (aggressive, physical (non-aggressive), verbal, and resistant to care) while controlling for resident demographics and health related characteristics.

4.1.5 Hypotheses

It is predicted that there will be a positive association between living in an SCU and the four subgroups of behavioral issues (aggressive, physical (non-aggressive), verbal, and resistant to care), controlling for resident demographics and health-related characteristics.

4.2 Methods

Descriptive statistics and multivariate analyses were used in this cross sectional study of 2010 National Survey of Residential Care Facilities (NSRCF) data. Resident characteristics, including demographic and health-related, facility characteristics, and behavioral issues were described and analyzed across type of RC/AL unit, including traditional (non-SCU) and SCU.

Ten behaviors measured by the 2010 NSRCF were grouped into four subgroups: aggressive, physical (non-aggressive), verbal, and resistant to care. Ordered logit regressions were used to find the association between the four behavioral subgroups and whether or not the resident lives in an SCU, controlling for characteristics of residents and facilities.

4.2.1 Sample

Data from the 2010 National Survey of Residential Care Facilities (NSRCF) were used. NSRCF facility and individual data were collected by the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics (NCHS), Division of Health Care Statistics. NSRCF residential care facilities had to be registered, licensed, listed, certified, or otherwise regulated by the state; have four or more licensed, certified, or registered beds; have at least one resident currently living in the facility; and provide room and board with at least two meals a day, around the clock on-site supervision, and help with personal care or health related services.

The 2010 NSRCF used a stratified two-stage probability sample design with interviews conducted in 2,302 facilities. The data were collected using interviews with

facility administrators and other staff members. Residents were not interviewed during this survey. Two publicly available data sets are available: a facility level data set and an individual (resident) level data set. This study uses the resident, individual level data set with each RC/AL resident representing one unit of analysis in this study.

4.2.2 Measures

Dependent Variable – The dependent variable of this study is whether the RC/AL resident has had a behavioral issue episode in the past 30 days. This variable is a count variable.

The ten behavioral issues identified in this study include: physically aggressive, ruining property, unwanted sexual advances, wandering, moving or taking property, removing clothing in public, verbal threats, noisy or makes disturbances, refusing medication, and refusing to bathe or clean. Each resident was coded as '0' if the resident had not exhibited this behavior in the past 30 days. Residents were attributed a '1' if the resident had exhibited this behavior "sometimes (includes one time)" in the past 30 days. Residents were coded as a '2' if the resident had exhibited this behavior "often" in the past 30 days.

The ten behavioral issues were then separated into four subgroups (Y1-Y4): Y1 = aggressive, Y2 = physical (non-aggressive), Y3 = verbal, and Y4 = resistant to care. Physically aggressive, ruining property, and unwanted sexual advances were grouped as aggressive behavioral issues. Wandering, moving or taking property, and removing clothing in public were classified as physical, non-aggressive, behavioral issues. Verbal threats and noisy or makes disturbances were classified as verbal behavioral issues.

Finally, refusing medication and refusing to bathe or clean were grouped together as resistant to care behavioral issues.

For each subgroup, residents' scores were calculated by adding together the responses for the corresponding behavioral issues. With three aggressive behavioral issues identified and residents scoring a 0, 1, or 2 on each of these three issues, a resident could score between 0 and 6 for the behavioral issue aggressive (Y1). With three physical, non-aggressive, behavioral issues identified and residents scoring a 0, 1, or 2 on each of these three issues, a resident could score between 0 and 6 for the behavioral issue physical, non-aggressive (Y2). With two verbal behavioral issues identified and residents scoring a 0, 1, or 2 on each of these three issues, a resident could score between 0 and 4 for the behavioral issue verbal (Y3). With two resistant to care behavioral issues identified and residents scoring a 0, 1, or 2 on each of these three issues, a resident could score between 0 and 4 for the behavioral issue resistant to care (Y4).

Independent Variables – The main independent variable of interest is whether the resident lives in an SCU or not. This variable is coded as a dichotomous variable with residents living in SCU coded as a '1' and residents living in traditional, non-SCUs coded as a '0.' The other independent variables include: resident demographics and health-related characteristics.

Resident demographic variables include: age, gender, race/ethnicity, English proficiency, education, marital status, length of stay (LOS), and Medicaid participation. Residents were separated into three groups for age: 18-64, 64-84, 85+ years of age. Gender was coded as a dichotomous variable with male = 0 and female = 1. The

race/ethnicity variable had five groups: Hispanic/Latino, White/Caucasian, Black/African American, Asian, and other. English proficiency was measured as an ordinal variable with residents classified into six groups of English speaking proficiency: excellent, very well, well, fair, poor or not at all, and does not speak. Residents were split into two groups for education level: high school or less and college or more. Residents' marital status fell in one of five groups: married, divorced, legally separated, widowed, and never married. Residents who have lived in the RC/AL facility for less than a year were coded as a 0 for LOS while residents who have lived in the facility for over a year were coded as a 1. The Medicaid participation variable was coded as a dichotomous variable with residents participating in Medicaid receiving a 1 and all others receiving a 0.

Resident health related characteristics include: overall health, assistance with activities of daily living (ADLs), incontinence issues, mental health issues, confusion problems, and memory problems. Overall health was coded as an ordinal variables with the following categories: excellent, very good, good, fair, poor. Eight separate ADLs are identified in the NSRCF database. These 8 ADLs include assistance with: transfers, walking, bathing/showering, dressing, eating, leaving the facility, using the toilet, and evacuating the facility. Assistance with ADLs was separated into two groups: resident needs assistance with less than five ADLs and resident needs assistance with five or more ADLs. Urinary incontinence and bowel incontinence were each coded as dichotomous variables. Residents with urinary incontinence issues were coded as a 1 and residents without urinary incontinence issues were coded as a 0.

Four mental health issues (Alzheimer's disease, depression, schizophrenia, and other mental health issue), confusion, short-term memory problems, and long-term memory problems were included as dichotomous variables (0 = not present, 1 = present). Confusion was coded as a 1 if the respondent answered the following question with "yes": Is [the resident] limited in any way because of difficulty remembering or because [the resident] experiences periods of confusion? Short term memory problem was coded as a 1 if the respondent answered the following question with "yes": During the last 7 days, has [the resident] given evidence of a problem with short-term memory, such as difficulty remembering what(he/she) had for breakfast or something you told (he/she) a few minutes earlier? Long term memory problem was coded as a 1 if the respondent answered the following question with "yes": During the last 7 days, has [the resident] given evidence of a problem with long-term memory, such as forgetting how old (he/she) is or forgetting that (he/she) was married.

4.2.3 Analyses

Descriptive statistics and multivariate analyses were used in this cross sectional study of behavioral issues among residents in RC/ALs. Resident characteristics, including demographic and health-related, and behavioral issues were described and analyzed across type of RC/AL unit, including traditional (non-SCU) and SCU.

Ordered logit regressions were used to find the association between the four behavioral subgroups and whether or not the resident lives in an SCU, controlling for demographic and health-related characteristics of residents.

Four models of analysis were used for each of the behavioral issue subgroups. Model #1 analyzed the relationship between one of the four behavioral issue subgroups (Y1-Y4) and whether or not the resident lives in an SCU. Model #2 analyzed the relationship between one of the four behavioral issue subgroups (Y1-Y4) and whether or not the resident lives in an SCU, while controlling for resident demographics. Model #3 analyzed the relationship between one of the four behavioral issue subgroups (Y1-Y4) and whether or not the resident lives in an SCU, while controlling for resident health-related characteristics. Finally, model #4 analyzed the relationship between one of the four behavioral issue subgroups (Y1-Y4) and whether or not the resident lives in an SCU, while controlling for resident demographics and resident health-related characteristics. Statistical significance for each of the Models' odds ratios was set at the p-value threshold of less than 0.05.

4.3 Results

Residents living in SCUs had higher percentages of behavior issues in each of the four behavior subgroups, compared to residents living in traditional, non-SCUs. Over 23% of SCU residents had exhibited aggressive behavioral issues in the past 30 days compared to 7% of resident living in non-SCUs. A staggering 56% of residents living in SCUs had exhibited physical, non-aggressive, behavioral issues compared to 14% of residents living in non-SCUs. Approximately 37% of SCU residents had exhibited verbal behavioral issues compared to 15% of non-SCU residents. Almost half of all SCU residents (45%) were resistant to care in the past 30 days compared to 22% of non-SCU residents.

Statistical significance was measured using Pearson Chi-Squared test statistic for difference in proportions. The null hypothesis states that the percentage of SCU residents is equal to the percentage of non-SCU residents and the difference seen in the statistics is due to chance. The alternate hypothesis states that the SCU proportion is not equal to the non-SCU proportion. Statistics with a p-value less than 0.05 reject the null hypothesis and are starred (*) in table 11.

Table 11 Percentage of residents with behavioral issues exhibited in the past 30 days for Residential Care/Assisted Living (RC/AL) residents living in traditional units (non-SCUs) and special care units (SCUs) * p-value<0.05 difference in proportions test

Behavioral Issues		**All Residents (N = 8,094)**	**Residents in Traditional Unit (NOT SCU) (N = 7,178)**	**Residents in SCUs (N = 916)**
Variables	**Categories**	**%**	**%**	**%**
Aggressive	Physically Aggressive	9.3	7.0*	23.7*
	Ruining Property			
	Unwanted Sexual Advances			
Physical, Non-aggressive	Wandering	20.1	14.3*	56.2*
	Moving/Taking Property			
	Removing Clothing in Public			
Verbal	Verbal Threats	18.2	15.2*	36.6*
	Noisy/ Disturbances			
Resistant to Care	Refusing Medication	25.2	22.0*	44.7*
	Refusing to bathe/clean			

Multivariate analyses for Models #1-4 are shown in table 12 below. For the behavioral issue subgroup aggressive (Y1), the ordered log-odds (logit) regression odds

ratio is 3.88 for Model #1. This means that for residents living in an SCU, the odds of higher scores for the behavioral issue aggressive are 3.88 times greater than the combined middle and lower scores for aggressive. In other words, for residents living in an SCU, the odds of higher scores for the behavioral issue aggressive, compared to the combined middle and lower scores in aggressive, increase by 288%. This positive association increases when looking at aggressive behavioral issues and controlling for resident demographics in Model #2. For residents living in an SCU, the odds of higher scores for the behavioral issue aggressive are 4.44 times greater than the combined middle and lower scores for aggressive, while controlling for resident demographics. The positive association between aggressive behavioral issues and living in an SCU is still present when controlling for resident health-related characteristics in Model #3 and when controlling for both resident demographic and health-related characteristics in Model #4. For residents living in SCUs, the odds of higher scores for the behavioral issue aggressive, compared to the combined middle and lower scores for aggressive, increase by 89%, while controlling for both resident demographics and health-related characteristics.

For the behavioral issue subgroup physical, non-aggressive (Y2), the ordered log-odds (logit) regression odds ratio is 9.03 for Model #1. For residents living in an SCU, the odds of higher scores for the behavioral issue physical are 9.03 times greater than the combined middle and lower scores for physical, non-aggressive. In other words, for residents living in an SCU, the odds of higher scores for the behavioral issue physical, compared to the combined middle and lower scores in physical, increase by

803%. When controlling for resident demographics (Model #2), in SCU residents, the odds of higher scores for the behavioral issue physical are 9.98 times greater than the combined middle and lower scores for physical, non-aggressive. When controlling for resident health-related characteristics (Model #3), the odds of higher scores for the behavioral issue physical increase by 196% in SCU residents, compared to the combined middle and lower scores for physical, non-aggressive. For residents living in SCUs, the odds of higher scores for the behavioral issue physical are 3.10 times greater than the combined middle and lower scores for physical, non-aggressive, controlling for resident demographics and health-related characteristics (Model #4).

For the behavioral issue verbal (Y3), the ordered log-odds (logit) regression odds ratio is 3.26 for Model #1. For residents living in an SCU, the odds of higher scores for the behavioral issue verbal are 3.26 times greater than the combined middle and lower scores for verbal. For residents living in an SCU, the odds of higher scores for the behavioral issue verbal, compared to the combined middle and lower scores in verbal, increase by 226%. For SCU residents, the odds of higher scores for the behavioral issue verbal are 3.84 times greater than the combined middle and lower scores for verbal, while controlling for resident demographics (Model #2). When controlling for resident health-related characteristics in Model #3, the odds of higher scores for the behavioral issue verbal increase by 57% in SCU residents, compared to the combined middle and lower scores for verbal behavioral issues. When controlling for both resident demographics and health-related characteristics in Model #4, the odds of higher scores

for the behavioral issue verbal are 1.71 times greater than the combined middle and lower scores for verbal.

For the behavioral issue resistant to care (Y4), the ordered log-odds (logit) regression odds ratio is 3.09 for Model #1 and 1.34 in Model #4. For residents living in an SCU, the odds of higher scores for the behavioral issue resistant to care are 3.09 times greater than the combined middle and lower scores for resistant to care. For residents living in an SCU, the odds of higher scores for the behavioral issue resistant to care, compared to the combined middle and lower scores in resistant to care, increase by 34% when controlling for both resident demographics and health-related characteristics (Model #4).

The odds ratios for the behavioral issue resistant to care (Y4) follow the same trend as the odds ratios for all other behavioral issue subgroups (Y1-Y3). The positive association is present in Model #1, across all behavioral issue subgroups. This positive association increases when resident demographics are held constant in Model #2. The odds ratios decrease, but remains positive, when resident health-related characteristics are controlled for in Model #3. When controlling for both resident demographics and health-related characteristics in Model #4, the odds ratios are higher than those in Model #3 and lower than the odds ratios in Models #1 and #2.

Table 12 Ordered logit regressions – Ordered log-odds (logit) regression odds ratios for residents living in SCUs across each behavioral issue group (Y1-Y4) * p-value<0.05

	Behavioral Issue (Y1-Y4)			
	Aggressive (Y1)	**Physical, non-aggressive (Y2)**	**Verbal (Y3)**	**Resistant to Care (Y4)**
Model #1: SCU (X1)	3.88*	9.03*	3.26*	3.09*
Model #2: SCU & Demographic (X1, X2)	4.44*	9.98*	3.84*	3.11*
Model #3: SCU & HR (X1, X3)	1.73*	2.96*	1.57*	1.33*
Model #4: SCU & Demographic & HR (X1, X2, X3)	1.89*	3.10*	1.71*	1.34*

4.4 Discussion

This overwhelming presence of behavioral issues indicates the need for additional mental health services provided in RC/ALs, particularly in SCUs. With the lack of policies and regulations protecting individuals living in SCUs, the current state of LTSS may not be equipped to serve residents suffering from behavioral symptoms.

The abundance of these behavioral issues seen in SCUs may be negatively influencing staff-to-resident interactions. With a higher percentage of SCU residents exhibiting aggressive behavioral issues compared to non-SCU residents, the risk of staff exposure to workplace violence must be considered.

Among NH residents living with dementia, the presence of behavioral issues and symptoms are pervasive (Kolanowski, Litaker, Buettner, Moeller, & Costa, 2011; Lyketsos et al., 2001). A study done in Texas reports both dementia and depression are associated with the risk of abuse and neglect in older people (Dyer, Pavlik, Murphy, & Hyman, 2000). Similarly, the presence of behavioral issues in SCUs may influence the risk of abuse in this care setting, including staff-to-resident, resident-to-resident, and resident-to-staff abuse.

These results suggest that perhaps RC/ALs are admitting residents into SCUs based on behavioral symptoms rather than diagnoses and resulting medical needs. SCUs are not psychiatric facilities equipped to prevent and treat behavioral symptoms and should not be used as such.

This study is not without its limitations. First, the NSRCF data has been cleaned and categorized to protect the identity of the residents and of the facilities that participated in the study. Because of this, the breakdown of categories may be oversimplifying the relationship between the studied variables.

Second, the 2010 NSRCF gathered data on residents by interviewing facility staff members. The data provided is self-reported by the facility rather than individual residents. This data source may not be the most accurate account of individual characteristics and is a limitation that must be considered when interpreting results in this study.

Despite these limitations, this study reports that behavioral issues are prevalent among SCU residents and there is a positive association between living in an SCU and

each of the four behavioral issue subgroups, controlling for demographic and health-related characteristics of residents. Currently, RC/AL SCUs have no concrete, legal definition to make services/care practices provided in SCUs transparent. This lack of transparency and consequent variability across SCUs may be allowing facilities to provided subpar care. Policies are needed to address this lack of an SCU definition and lack of protections afforded to vulnerable individuals living in SCUs with Alzheimer's disease and dementia.

5. CONCLUSIONS

Alzheimer's Special Care Units in Residential Care and Assisted Living Facilities finds that there is variability across RC/AL SCUs when it comes to unit features and less than 5% of RC/ALs in the United States have a "standard" SCU (contain all 5 of the minimum dementia care features). There are not enough facilities with the five minimum dementia care features to meet the growing demand for memory care in long-term care facilities.

When looking at SCUs from an individual or resident level, *Alzheimer's Special Care Unit Residents Living in Residential Care and Assisted Living Facilities: Comparing SCU to Non-SCU Residents across Resident Characteristics, Falls, ER visits, and Hospital Stays* finds that residents in SCUs have similar demographic characteristics as residents in traditional, non-SCUs; however, these two groups differ in health-related characteristics with residents living in SCUs reporting poorer overall health, having lower participation in Medicaid, and having much higher rates of urinary incontinence, bowel incontinence, confusion issues, memory problems, and mental health issues/diagnoses, including Alzheimer's disease. Residents living in SCUs had higher percentages of falls resulting in a hip fracture or other injury compared to residents living in traditional, non-SCUs.

Finally, *Behavioral Issues in Alzheimer's Special Care Unit Residents Living in Residential Care and Assisted Living Facilities* finds that behavioral issues are prevalent among SCU residents and there is a positive association between living in an SCU and

each of the four behavioral issue subgroups, controlling for demographic and health-related characteristics of residents.

The 2001 National Bioethics Committee identified six categories of vulnerability including: cognitive/communicative vulnerability, institutional vulnerability, deferential vulnerability, medical vulnerability, economic vulnerability, and social vulnerability (National Bioethics Advisory Commission, 2001). Cognitive/communicative vulnerability can be capacity-related, situational, or communicative. Cognitively impaired adults, including individuals living with Alzheimer's disease or other dementias, are included in capacity-related cognitive vulnerability as individuals lacking the ability to make decisions on their own. Institutional vulnerability includes individuals who may or may not have the capacity to make their own decisions but are subject to the formal authority of others. This formal authority can derive from an individual or a caregiving setting, including RC/AL. Deferential vulnerability is very similar to institutional vulnerability, except the subordination is due to an informal authority or an inequality of power and knowledge. Doctor-patient relationships often fall under the domain of deferential vulnerability. Medical vulnerability is present when individuals have a serious medical ailment that may influence their decision making abilities. Economic vulnerability is seen when individuals are disadvantaged due to the lack of social goods and services. Social vulnerability deals with stereotyping certain groups because of the social/cultural perception of that particular group (National Bioethics Advisory Commission, 2001).

Of the six types of vulnerability, individuals living in RC/AL SCUs with Alzheimer's disease or other dementias are subject to at least four types: cognitive/communicative, institutional, deferential, and medical. Many times SCU residents are cognitively impaired or unable to articulate their decisions and medical needs. Also, SCU residents are subject to institutional and deferential vulnerability due to the formal and informal pressures of caregiving in an RC/AL setting. Residents living in RC/AL SCUs are extremely vulnerable and should be protected through policies and research. Policies are needed to address the lack of an SCU definition and the lack of protections afforded to vulnerable individuals living in SCUs with Alzheimer's disease and dementia.

5.1 Summary

The number of RC/ALs is growing in the United States as the population ages. These facilities differ from nursing homes and other long-term care facilities by licensure status, structure, culture, payer mix, services, staffing, and resident case mix. As the number of individuals diagnosed with Alzheimer's disease and other forms of dementia has increased, the demand for memory care services in residential long-term care facilities has grown. Many RC/ALs offer specialized, memory care in the form of Special Care Units (SCUs); however, little is known about these units, the ways in which staffing, services, and environment may differ from traditional ALFs, and the association between these units and quality of care/quality of life experienced by residents.

With the increasing need for dementia specific care and the social and political push away from NHs and, subsequently, toward RC/ALs, it is important to understand

the nature and characteristics of SCUs. According to the analyses in *Alzheimer's Special Care Units in Residential Care and Assisted Living Facilities*, approximately 20% of RC/ALs have an SCU and a little over 20% of these RC/ALs have an actual SCU that provides all five features of dementia care. This means that in this country, less than 5% of RC/ALs have a good SCU. There are not enough facilities with the five minimum SCU criteria to meet the growing demand for memory care in long-term care facilities.

The analyses in *Alzheimer's Special Care Unit Residents Living in Residential Care and Assisted Living Facilities: Comparing SCU to Non-SCU Residents across Resident Characteristics, Falls, ER visits, and Hospital Stays* reports that residents in SCUs have similar demographic characteristics as residents in traditional, non-SCUs; however, these two groups differ in health-related characteristics with residents living in SCUs reporting poorer overall health, having lower participation in Medicaid, and having much higher rates of urinary incontinence, bowel incontinence, confusion issues, memory problems, and mental health issues/diagnoses, including Alzheimer's disease. Residents living in SCUs had higher percentages of falls resulting in a hip fracture or other injury compared to residents living in traditional, non-SCUs.

The analyses in *Behavioral Issues in Alzheimer's Special Care Unit Residents Living in Residential Care and Assisted Living Facilities* reports that behavioral issues, including aggressive, physical (non-aggressive), verbal, and resistant to care behavioral symptoms, are prevalent among SCU residents and there is a positive association between living in an SCU and each of the four behavioral issue subgroups, when controlling for demographic and health-related characteristics of residents.

Currently, RC/AL SCUs have no concrete, legal definition to make services/care practices provided in SCUs transparent. This lack of transparency and consequent variability across SCUs may be allowing facilities to provided subpar care. Policy recommendations include: federal or increased state regulation and oversight, physical restraint free care, and chemical restraint stewardship. Policies are needed to address this lack of an SCU definition and lack of protections afforded to vulnerable individuals living in SCUs with Alzheimer's disease and dementia.

5.2 Contribution

This study has implications for long-term care stakeholders and for those policy-makers that seek to protect a particularly vulnerable population, cognitively impaired adults. Currently, very little is known about SCUs in RC/ALs and the services provided in these units. The analyses completed in this study are one of the first few steps in understanding the complexities of providing quality of care and quality of life for vulnerable residents living in RC/AL SCUs.

5.3 Future Research

Future research should focus on other indicators of quality of care and quality of life for residents living in RC/AL SCUs. A fall resulting in hip fracture or other injury is one of a broad array of quality indicators, including structure, process, and outcome measures (Donabedian, 1966). It would be interesting to study how living in an SCU is associated with presence of pressure ulcers, use of antipsychotic drugs, and change in assistance with ADLs.

Also, research is needed to better understand the complexities surrounding staff-to-resident interactions, informal and formal caregiver burnout, and psychosocial factors associated with seeking help to care for people with Alzheimer's disease and dementia. This research might look at the forces behind entry into an RC/AL SCU and the roll staff and staff training takes in the care of residents living in SCUs.

Research concerning RC/AL SCUs and payment would be a valuable addition to the long-term care body of knowledge. A cost-effectiveness analysis for RC/AL SCUs could illuminate whether or not long-term care consumers are receiving a cost-effective model of care compared to other long-term care options. Also, the relationship between RC/AL SCUs and payment type, specifically Medicaid, could lead to better understanding SCUs and what is needed to better protect individuals residing in SCUs.

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